Needs Assessment of Persons with Disabilities in the NWT – **Summary Report**

Photo Credits
Tim Atherton: top left, top right & bottom right of cover, pages 10 and 24. Northern News Services Ltd: middle photos on cover, pages 14 and 16. Hillary Soderberg: page 1. Fran Hurcomb: page 7. Cecily Hewitt: page 9. Special Olympics: page 23.

Living with Disability.... Living with Dignity

Needs Assessment of Persons
with Disabilities in the NWT
Summary Report

Research conducted by
Lois Little, Sandy Auchterlonie
and Bob Stephen of Lutra Associates Ltd.
on behalf of the partnership of:

NWT Council for Disabled Persons
GNWT Health and Social Services
Yellowknife Association for Community Living
GNWT Education, Culture and Employment (College and Careers Division)
YWCA of Yellowknife
Human Resources Development Canada
MaryAnne Duchesne

October 2000

Acknowledgments

The research team from Lutra Associates Ltd. wishes to acknowledge the particularly strong commitment and dedication to enabling the voices of persons with disabilities to be heard.

Marlene Wolki, Bill Kudluk and Trudy McClements, Paulatuk

Alice Kimiksana, Barbara Memogana and Tony Kulbisky, Holman

Shirley Esau and Lorna Dillon, Sachs Harbour

Lucy Dillon and Vera Ovayak, Tuktoyaktuk

Wendy Mepham and Barb Lennie, Inuvik

Kim McLeod, Jackie Ryan and Edna Alexi, Fort McPherson

Carol Norwegian, Courtnae Clark and Corrine Dillon, Tsiigehtchic

Gladys Edwards, Diane Gordon and Shauna Gordon, Aklavik

Sharon Tutcho, Colville Lake

Phoebe McNeeley, Fort Good Hope

Andrea Dougherty, Elaine Doctor and Lillian Doctor, Tulita

Tony Harrison, Norman Wells

Carolyn Yukon, Deline

Leah Keats, Fort Simpson

Faye Stark and Leonie Sabourin, Fort Providence

Susan Kotchea, Bernice Hardisty and Marie Kotchea, Fort Liard

Noleen Villebrun, Fort Resolution

Betty Lyons, Hay River

Sharon Sunrise and Rita Plunkett, Hay River Reserve

Sister Agnes Sutherland, Pamela Bradley and Sylvie Tordiff, Fort Smith

Linda McConnell, Alestine Mantla and Rachel Ann Liske, Rae-Edzo

Mary Jane Tsetta, Ndilo

Aggie Brockman, Vita Morin, Jeff Miniely, Sue Edmonds and Donna Allen, Yellowknife

Helene Usherwood, Christina Vernon, Jan Stirling and Barb Beaton, Yellowknife

Doreen Ann Apple, Rae Lakes

Etonia Hardisty, Wrigley

Lucy Simon, Jean Marie River

Ruby Jumbo and Brenda Jumbo, Trout Lake

We also want to thank the people on the Disabilities Needs Assessment Project Working Group:

Aggie Brockman, NWT Council for Disabled Persons

Miriam Wideman and Lani Cooke, Yellowknife Association for Community Living

Kate Tymstra, YWCA

MaryAnne Duchesne, self-advocate

Bernie Karpan, Mary-Jane Stewart, Cecily Hewitt and Agnes Mackay, GNWT Health and Social Services

Wendy McPherson, GNWT Education, Culture and Employment (College and Careers)

Angela Ballard, GNWT Education, Culture and Employment (College and Careers)

Barbara Deakin, Metis Nation of the NWT

Thomas Shepherd, Human Resources Development Canada

A full report on the Needs Assessment is available from the partners.

Table of Contents

103-04151/

Page

1. About the Needs Assessment 1
- Disability 1
- Why a Needs Assessment? 1
- The Process 2
- Who Participated 3
- Disability in the NWT in the Future 5
- Caution: When Using This Information 5

2. The Disabilities We Have 7

3. The Reasons for Disability 9

4. Who We Are 10
- Gender and Age 10
- Place of Residence 10
- Ethnicity and Language 10
- Marital Status and Dependents 11
- Education, Employment and Income 11
- Work, Home, School, Social, Recreation and Leisure Activities 12

5. Aids and Supports 14

6. Use and Need for Programs and Services 16
- Medical Health Services 16
- Social and Mental Health Supports 16
- Accommodation/Housing Services 18
- Income 18
- Life Skills, Employment and Residential Supports 18
- Education and Training for Adults 18
- Education and Training for Children 19
- Legal and Protection Services 19
- Information, Advocacy and Other Programs and Services 19

7. Caregivers 20

8. Programs and Services – Best Practices 23

9. Taking Action 24

Page

Tables

1: 1999 NWT Population and Needs Assessment Respondents with Disability by Age, 2000 4

2: Degree of Severity of Disability by Percent of the NWT Population with Disability 5

3: The Number of NWT Persons with Moderate to Severe Disability Using Services Now, Needing Services and Not Getting Them Now by Main Type of Program/Service, 2000 and Expected Demand in 2004 and 2009 17

Figures

1: Percent of Needs Assessment Participants Having an Assessed/Diagnosed/Named Disability, 2000 8

2: The Main Reported Reason for Disability Among Persons with Disability, NWT Needs Assessment 2000 9

3: Formal Education of Adults with Disability Participating in the Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey 11

4: Employment Activity Among Adults with Disability by Ethnicity, NWT Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey 12

5: Daily Social, Recreation and Leisure Activities of Persons with Disability by Percent, NWT Needs Assessment 2000 12

6: Main Problems Faced in Daily Living by Age, NWT Needs Assessment 2000 13

7: Main Problems Faced in Daily Living by Type of Disability, NWT Needs Assessment 2000 13

8: Use of Special Aids/Equipment/Supports by Type of Disability, NWT Needs Assessment 2000 14

9: Main Special Aids/Equipment/Support Used and Needed by Type of Disability, NWT Needs Assessment 2000 15

10: Difficulties Encountered With and Without the Use of Special Equipment/Aids/Support by Frequency, NWT Needs Assessment 2000 15

11: Personal Challenges Faced by Parents/Caregivers, NWT Needs Assessment 2000 20

12: Other Challenges Faced by Parents/Caregivers, NWT Needs Assessment 2000 21

13: Good" Things About Caring for Persons with Disability by Percent of Parents/Caregivers, NWT Needs Assessment 2000 21

14: Programs and Service Used by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000 22

15: Programs and Services Needed by Parents/Caregivers of Persons with Disability Participating in the Needs Assessment, 2000 22

1. About the Needs Assessment

Disability

Disability is described by the World Health Organization (WHO) as *"the loss or reduction of functional ability and activity due to any disturbance of, or interference with, the normal structure and functioning of the body, including the systems of mental function."* In this Needs Assessment, a more simplified definition is used. **A disability is any degree of physical, sensory, psychiatric, cognitive, intellectual or learning limitation which causes difficulty in the usual activities of daily living**. Persons with disability may experience varying degrees of limitation ranging from mild to moderate to severe. Difficulties in usual activities of daily living may result from limitations caused by one or more disabilities, for example a physical disability and a learning disability.

Disability can affect people of all ages and from all backgrounds. Persons may be born with disability. Some may develop a disability over the course of their life. In addition to persons with disability, parents, unpaid caregivers and community service providers are other people who are affected by disability.

Why a Needs Assessment?

The Canada Census identifies people with disability in the NWT and asks these people to participate in the Health and Activity Limitation Survey (HALS). The HALS asks people to describe their disability in detail. HALS information tells us that over 5,400 people in the NWT may have a disability.[1]

HALS:

- collects information on mobility, agility, seeing, hearing and speaking disability among adults in the NWT but very little information on children.
- groups persons with intellectual, learning, cognitive and psychiatric disabilities together as 'other' disabilities, so we really don't know much about these disabilities.
- does not collect information about other people in the NWT who are affected by disability, for instance parents and caregivers.
- does not release information on disability by NWT community or region.

1 Based on 1991 HALS and the Government of the NWT (GNWT) 1999 population estimates for the new Northwest Territories (excluding Nunavut). These numbers do not include persons with disability living in institutions.

The gaps in information about disability make it difficult to plan and allocate resources to assist persons affected by disability. In 1998, a partnership was formed to conduct a Needs Assessment of Persons with Disabilities in the NWT. Over the course of the Needs Assessment, two levels of government, a First Nation organization, territorial and community-based non-government organizations and a self-advocate participated in the partnership.

The NWT Council for Disabled Persons coordinated the Needs Assessment.

The Process

The purpose of the Needs Assessment was to **determine the nature and distribution of disabilities within the NWT population, and the gaps in, and future requirements for, services among this population**. This would be done by developing an information base on:

- the number and percentage of the NWT population with intellectual, sensory and/or physical disabilities; the nature and distribution of these disabilities; day-to-day living needs by main type of disability; and issues faced by persons with these disabilities and the issues faced by their families.
- existing programs/services available to persons affected by intellectual, sensory and/or physical disabilities, and the current and projected (5–10 year) service needs of this population.

After beginning work on the Assessment, the partners broadened the study to include:

- cognitive and learning disabilities.
- psychiatric disabilities where this disability accompanied one or more of the other disabilities under investigation.[2]

Both diagnosed and undiagnosed disabilities acknowledged by persons with disability or his/her parent/caregiver were included in the Assessment.

The partners were:

- NWT Council for Disabled Persons
- GNWT Health and Social Services
- Yellowknife Association for Community Living
- GNWT Education, Culture and Employment (College and Careers Division)
- YWCA of Yellowknife
- Human Resources Development Canada
- MaryAnne Duchesne (self-advocate)

The Metis Nation of the NWT was also a partner between August and December 1999.

2 GNWT Health and Social Services is committed to completing a separate needs assessment of persons with psychiatric disability.

The Needs Assessment partners and the research team from Lutra Associates collaborated to:

- develop definitions of disability
- design and test questionnaires to collect information from community service providers, persons with disability, and parent/caregivers.
- identify information needed from regional program managers.
- inform people about, and encourage participation in, the Assessment.

At the front line, workers in all NWT communities were asked to collaborate to identify and engage people with disability in this Assessment. Many front-line workers had difficulty dedicating time and priority to this Assessment due to heavy workloads, staff shortages and lack of client information.

Who Participated

This Needs Assessment heard from 1,259 people in the NWT who are affected in some way by disability. Questionnaires were completed by:

- 807 persons with disability who acknowledge their disability.[3]
- 227 parents/caregivers of persons with disability.
- 181 community service providers working for non-government and government agencies.
- 44 regional program managers were also interviewed.

Persons with disabilities who participated in this Assessment make up:

- 2% of the whole population in the NWT, and
- 15% of the NWT population with disability. (Table 1)

Children (0-14 years of age) make up:

- 27% of the population in the NWT, and
- 15.7% of persons with disability in the NWT. (Table 1)

Elderly people (65 years of age or more) comprise:

- 4% of the NWT population, and
- 16% of persons with disability in the NWT. (Table 1)

Compared to the whole NWT population with disability, this Assessment involved a greater proportion of elderly people, a similar proportion of children and a much smaller portion of adults. (Table 1)

The Needs Assessment of Persons with Disabilities was the first research to:

- assess the needs of persons with disabilities in the NWT, those who care for them and are not paid to do so, and those who are paid to provide services.
- be managed by a multi-interest partnership and coordinated by a non-government organization.

3 Acknowledgement of disability by the individual him/herself was required to participate in the Assessment.

The gaps in information about disability make it difficult to plan and allocate resources to assist persons affected by disability. In 1998, a partnership was formed to conduct a Needs Assessment of Persons with Disabilities in the NWT. Over the course of the Needs Assessment, two levels of government, a First Nation organization, territorial and community-based non-government organizations and a self-advocate participated in the partnership.

The NWT Council for Disabled Persons coordinated the Needs Assessment.

The Process

The purpose of the Needs Assessment was to **determine the nature and distribution of disabilities within the NWT population, and the gaps in, and future requirements for, services among this population**. This would be done by developing an information base on:

- the number and percentage of the NWT population with intellectual, sensory and/or physical disabilities; the nature and distribution of these disabilities; day-to-day living needs by main type of disability; and issues faced by persons with these disabilities and the issues faced by their families.
- existing programs/services available to persons affected by intellectual, sensory and/or physical disabilities, and the current and projected (5-10 year) service needs of this population.

After beginning work on the Assessment, the partners broadened the study to include:

- cognitive and learning disabilities.
- psychiatric disabilities where this disability accompanied one or more of the other disabilities under investigation.[2]

Both diagnosed and undiagnosed disabilities acknowledged by persons with disability or his/her parent/caregiver were included in the Assessment.

The partners were:

- NWT Council for Disabled Persons
- GNWT Health and Social Services
- Yellowknife Association for Community Living
- GNWT Education, Culture and Employment (College and Careers Division)
- YWCA of Yellowknife
- Human Resources Development Canada
- MaryAnne Duchesne (self-advocate)

The Metis Nation of the NWT was also a partner between August and December 1999.

2 GNWT Health and Social Services is committed to completing a separate needs assessment of persons with psychiatric disability.

The Needs Assessment partners and the research team from Lutra Associates collaborated to:

- develop definitions of disability.
- design and test questionnaires to collect information from community service providers, persons with disability, and parent/caregivers.
- identify information needed from regional program managers.
- inform people about, and encourage participation in, the Assessment.

At the front line, workers in all NWT communities were asked to collaborate to identify and engage people with disability in this Assessment. Many front-line workers had difficulty dedicating time and priority to this Assessment due to heavy workloads, staff shortages and lack of client information.

Who Participated

This Needs Assessment heard from 1,259 people in the NWT who are affected in some way by disability. Questionnaires were completed by:

- 807 persons with disability who acknowledge their disability.[3]
- 227 parents/caregivers of persons with disability.
- 181 community service providers working for non-government and government agencies.
- 44 regional program managers were also interviewed.

Persons with disabilities who participated in this Assessment make up:

- 2% of the whole population in the NWT, and
- 15% of the NWT population with disability. (Table 1)

Children (0-14 years of age) make up:

- 27% of the population in the NWT, and
- 15.7% of persons with disability in the NWT. (Table 1)

Elderly people (65 years of age or more) comprise:

- 4% of the NWT population, and
- 16% of persons with disability in the NWT. (Table 1)

Compared to the whole NWT population with disability, this Assessment involved a greater proportion of elderly people, a similar proportion of children and a much smaller portion of adults. (Table 1)

The Needs Assessment of Persons with Disabilities was the first research to:

- assess the needs of persons with disabilities in the NWT, those who care for them and are not paid to do so, and those who are paid to provide services.
- be managed by a multi-interest partnership and coordinated by a non-government organization.

3 Acknowledgement of disability by the individual him/herself was required to participate in the Assessment.

More than two-thirds of all persons with disability in the NWT have a mild disability. Persons with mild, "hidden", or less widely understood disabilities may not acknowledge disability. Also, they may not use or need programs/services to cope with disability. Persons with visible, moderate to severe and/or more widely understood disabilities such as physical or visual disability, are more likely to talk about them. This Assessment involved:

- 33% of all NWT persons with a moderate to severe degree of disability. (Table 2)
- only 2% of NWT persons with a mild degree of disability.

This Assessment found that a severe disability of one type may be accompanied by a moderate or mild disability of another type(s). The severity of disability can change over time.

- Cognitive disability is a degenerative condition which by definition, does get worse.
- Learning and intellectual disability do not change over time but personal, home and community factors can influence the extent to which these disabilities limit daily living activities.
- The degree of physical and sensory disabilities can worsen over time.

This Assessment found that 85% of persons with disability either don't know the future of their disability or expect it to get worse in the future. Uncertainty about the future may be due to limited understanding of the disability or hopes that services or aids can be found to manage the effects of the disability.

Disability is an intensely personal and emotional issue. Disability may be viewed negatively, not acknowledged or not understood.

- Generally, people with disability and parents/caregivers of persons with disability who are uncomfortable talking about disability chose not to participate in the Needs Assessment.

Table 1: 1999 NWT Population and Needs Assessment Respondents with Disability by Age, 2000

Age Groups	NWT Population	Needs Assessment Respondents with Disability	% of NWT Population with Disability[1]	Needs Assessment Respondents as a % of NWT Population
Total	**41,606**	**807**	**13.1%** N=5,453	**14.8%** N=807
Children 0-14 years	27.2%	12.7%	15.7%	12%
Adults 15-64 years	68.7%	51.5%	67.8%	11%
Elderly 65 + years	4.1%	32.2%	16.5%	29%
Unknown	-	3.6%	-	-

1. Estimate based on HALS 1991 and GNWT population estimates for 1999.

N = Number of Respondents

- People affected by disability who have participated in surveys in the past and seen no action from them, refused to participate in yet another survey.
- Some persons affected by disability, including community service providers, did not have the literacy skills to participate in the Assessment.

Some of these barriers were overcome by hiring community-based researchers to assist persons affected by disability to participate in this Assessment.

Disability in the NWT in the Future

In 1999, 1,780 persons with moderate to severe disability and 3,674 with mild disability lived in the NWT. By the year 2004, there may be 5,910 persons with disability, of which 1,982 will have moderate to severe disability. Most (81%) community service providers participating in this Needs Assessment expect that increases in the number of persons with disability will be driven by:

- the high use of alcohol, drugs and solvents.
- abuse/neglect.
- an aging population.

Caution: When Using This Information

The information in this Assessment is based on one-third of the 1,780 NWT citizens living in households who are identified as having a moderate to severe disability. This Assessment also documents the needs of parents/caregivers of persons with disability, which is the first time this information has been recorded.

Persons with moderate to severe disability each face unique personal and life circumstances, making it difficult to draw generalized conclusions about the entire population affected by disabilities.

It is important to note that while a non-random sampling technique was used in this research, the sample is large enough to provide a useful basis for planning programs and services and allocating resources to the needs of people with disabilities and families.

The Needs Assessment has five limitations.

1. The needs of persons with mild disability are not well understood through this Assessment.

Table 2: Degree of Severity of Disability by Percent of the NWT Population with Disability

Degree of Disability	NWT Persons with Disability in 1999[1] (N=5,453)		2000 Needs Assessment Percent of Persons with Disability (N=807)	
Mild/Slight	67%	(N=3,674)	2%	(N=85)
Moderate	23%	(N=1,259)	16.6%	(N=209)
Severe	10%	(N=521)	73%	(N=379)
Moderate/Severe	32.6%	(N=1,780)	33%	(N=588)

1. People living in households not institutions, based on the 1991 Health and Activity Limitation Survey.

N = Number of Respondents

More than two-thirds of all persons with disability in the NWT have a mild disability. Persons with mild, "hidden", or less widely understood disabilities may not acknowledge disability. Also, they may not use or need programs/services to cope with disability. Persons with visible, moderate to severe and/or more widely understood disabilities such as physical or visual disability, are more likely to talk about them. This Assessment involved:

- 33% of all NWT persons with a moderate to severe degree of disability. (Table 2)
- only 2% of NWT persons with a mild degree of disability.

This Assessment found that a severe disability of one type may be accompanied by a moderate or mild disability of another type(s). The severity of disability can change over time.

- Cognitive disability is a degenerative condition which by definition, does get worse.
- Learning and intellectual disability do not change over time but personal, home and community factors can influence the extent to which these disabilities limit daily living activities.
- The degree of physical and sensory disabilities can worsen over time.

This Assessment found that 85% of persons with disability either don't know the future of their disability or expect it to get worse in the future. Uncertainty about the future may be due to limited understanding of the disability or hopes that services or aids can be found to manage the effects of the disability.

Disability is an intensely personal and emotional issue. Disability may be viewed negatively, not acknowledged or not understood.

- Generally, people with disability and parents/caregivers of persons with disability who are uncomfortable talking about disability chose not to participate in the Needs Assessment.

Table 1: 1999 NWT Population and Needs Assessment Respondents with Disability by Age, 2000

Age Groups	NWT Population	Needs Assessment Respondents with Disability	% of NWT Population with Disability[1]	Needs Assessment Respondents as a % of NWT Population
Total	**41,606**	**807**	**13.1%** N=5,453	**14.8%** N=807
Children 0-14 years	27.2%	12.7%	15.7%	12%
Adults 15-64 years	68.7%	51.5%	67.8%	11%
Elderly 65 + years	4.1%	32.2%	16.5%	29%
Unknown	-	3.6%	-	-

1. Estimate based on HALS 1991 and GNWT population estimates for 1999

N = Number of Respondents

- People affected by disability who have participated in surveys in the past and seen no action from them, refused to participate in yet another survey.
- Some persons affected by disability, including community service providers, did not have the literacy skills to participate in the Assessment.

Some of these barriers were overcome by hiring community-based researchers to assist persons affected by disability to participate in this Assessment.

Disability in the NWT in the Future

In 1999, 1,780 persons with moderate to severe disability and 3,674 with mild disability lived in the NWT. By the year 2004, there may be 5,910 persons with disability, of which 1,982 will have moderate to severe disability. Most (81%) community service providers participating in this Needs Assessment expect that increases in the number of persons with disability will be driven by:

- the high use of alcohol, drugs and solvents.
- abuse/neglect.
- an aging population.

Caution: When Using This Information

The information in this Assessment is based on one-third of the 1,780 NWT citizens living in households who are identified as having a moderate to severe disability. This Assessment also documents the needs of parents/caregivers of persons with disability, which is the first time this information has been recorded.

Persons with moderate to severe disability each face unique personal and life circumstances, making it difficult to draw generalized conclusions about the entire population affected by disabilities.

It is important to note that while a non-random sampling technique was used in this research, the sample is large enough to provide a useful basis for planning programs and services and allocating resources to the needs of people with disabilities and families.

The Needs Assessment has five limitations.

1. The needs of persons with mild disability are not well understood through this Assessment.

Table 2: Degree of Severity of Disability by Percent of the NWT Population with Disability

Degree of Disability	NWT Persons with Disability in 1999[1] (N=5,453)		2000 Needs Assessment Percent of Persons with Disability (N=807)	
Mild/Slight	67%	(N=3,674)	2%	(N=85)
Moderate	23%	(N=1,259)	16.6%	(N=209)
Severe	10%	(N=521)	73%	(N=379)
Moderate/Severe	32.6%	(N=1,780)	33%	(N=588)

1. People living in households not institutions, based on the 1991 Health and Activity Limitation Survey.

N = Number of Respondents

2. "Hidden disabilities" or "brain-related disabilities" are not widely understood, accepted or acknowledged. Persons with these disabilities may have confused one disability for another. Others may not have recognized or acknowledged this disability and did not participate.
3. This Needs Assessment provides no new information on the characteristics of children with disability. Slightly more than 100 children with disability participated in this Assessment. Small numbers limit the extent to which definitive statements can be made about children with disability. At the same time as this Assessment was being done, NWT schools were assessing student needs including those of students with disabilities. Sharing information from the two Assessments will be important to understanding the needs of NWT children with disability.
4. Data presented on psychiatric disability refer only to those persons who have one or more of the other disabilities under investigation as well as a psychiatric disability. No definition of psychiatric disability was provided. Data on psychiatric disability should be treated as a very limited perspective of this disability. More complete information on psychiatric disability will be available when the GNWT Health and Social Services and its partners complete a mental health needs assessment.
5. Economies of scale significantly influence the human services/programs available to the NWT citizens. Larger communities have a greater range of programs/services. Program/service needs now and in the future may be under-represented by persons affected by disability living in smaller communities who are not exposed to program/service options. People don't ask for things that they do not know exist.

Should the needs of persons with mild disability change, for example due to employment or lifestyle circumstances, the needs presented in this Assessment would be severely under-represented. Just think about George!

George has a mild physical disability due to a back injury. When George changed jobs, he didn't realize that he would have to do more lifting and move heavier objects. His mild back problem is now causing a great deal of difficulty for him.

2. "Hidden disabilities" or "brain-related disabilities" are not widely understood, accepted or acknowledged. Persons with these disabilities may have confused one disability for another. Others may not have recognized or acknowledged this disability and did not participate.
3. This Needs Assessment provides no new information on the characteristics of children with disability. Slightly more than 100 children with disability participated in this Assessment. Small numbers limit the extent to which definitive statements can be made about children with disability. At the same time as this Assessment was being done, NWT schools were assessing student needs including those of students with disabilities. Sharing information from the two Assessments will be important to understanding the needs of NWT children with disability.
4. Data presented on psychiatric disability refer only to those persons who have one or more of the other disabilities under investigation as well as a psychiatric disability. No definition of psychiatric disability was provided. Data on psychiatric disability should be treated as a very limited perspective of this disability. More complete information on psychiatric disability will be available when the GNWT Health and Social Services and its partners complete a mental health needs assessment.
5. Economies of scale significantly influence the human services/programs available to the NWT citizens. Larger communities have a greater range of programs/services. Program/service needs now and in the future may be under-represented by persons affected by disability living in smaller communities who are not exposed to program/service options. People don't ask for things that they do not know exist.

Should the needs of persons with mild disability change, for example due to employment or lifestyle circumstances, the needs presented in this Assessment would be severely under-represented. Just think about George!

George has a mild physical disability due to a back injury. When George changed jobs, he didn't realize that he would have to do more lifting and move heavier objects. His mild back problem is now causing a great deal of difficulty for him.

2. *The Disabilities We Have*

If the types of disability experienced by Needs Assessment respondents with disability are typical of all NWT persons with moderate to severe disability:

- 88% have physical or sensory disability.
- 64% have physical disability.
- 32% have learning disability.
- 29% have visual disability.
- 27% have hearing disability.
- 25% have intellectual disability.
- 20% have cognitive disability.
- 19% have speech disability.
- 10% also have a psychiatric disability.

Six of every ten people with disability participating in this Assessment have more than one disability.

Among children 0-14 years of age who participated in this Assessment:

- 70% have learning disability.
- 56% have intellectual disability.
- 50% have speech disability.

"Doctors don't know about Dene medication. They don't understand us elders."

(from Personal Questionnaire)

Among persons 15-64 years of age who participated in this Assessment:

- 64% have physical disability.
- 34% have learning disability.
- 28% have intellectual disability

Among persons 65 or more years of age who participated in this Assessment:

- 78% have physical disability.
- 41% have hearing disability.
- 27% have cognitive disability.

"Loudspeakers and public address announcements are rarely clear. Theatres are TOO loud and blast you. We need to educate and make the public aware of hearing needs."

(from Personal Questionnaire)

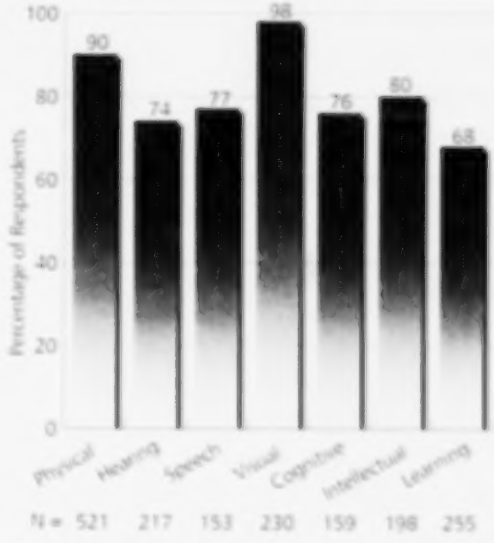
Assessment and diagnostic services for persons with disability are not available in all NWT communities on a regular basis. Those who have not had their disability assessed, diagnosed or named by a professional, may not acknowledge their disability and would not have participated in this Assessment. In this Assessment:

- 92% of persons have disabilities which have been assessed, diagnosed or named by a professional.
- persons with a visual disability are most likely to have an assessed/ diagnosed/named disability.
- persons with learning disability are least likely to have their disability assessed/ diagnosed/named. (Figure 1)

"There are no services for the disabled in this community, no advocacy."

(from Personal Questionnaire)

Figure 1: Percent of Needs Assessment Participants Having an Assessed/Diagnosed/ Named Disability, 2000



Note:

1. *N = Number of Respondents*
2. *Among those people identifying a psychiatric disability in addition to one or more of the disabilities under investigation, 82% stated that the psychiatric disability had been assessed/diagnosed or named by a professional.*

3. The Reasons for Disability

The health and lifestyle circumstances of NWT residents are described in a Government of the NWT report entitled *The NWT Health Status Report* (Health and Social Services, 1999). Some health and lifestyle circumstances can lead to untimely death, illness/disease, injury or disability. These circumstances include poverty, poor nutrition, alcohol/drug use, and certain social and physical behaviours.

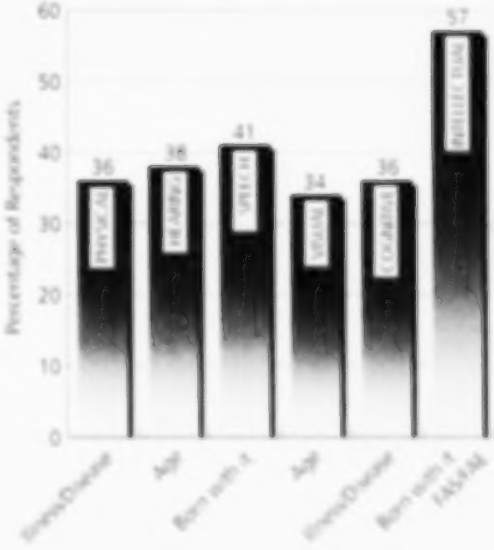
This Needs Assessment found that:

- many persons with disability live in poverty.
- illness/disease, age and the circumstances before, during and at birth are the main reasons for disabilities. (Figure 2)

"Dealing with difficulty is a way of life if that is all you've known."

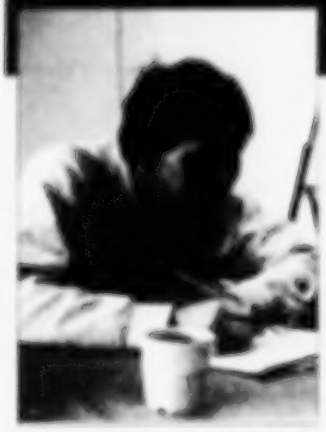
(from Personal Questionnaire)

Figure 2: The Main Reported Reason for Disability among Persons with Disability, NWT Needs Assessment 2000



"How can you do a health survey without reference to smoking? It has played hell with my breathing and circulation. It has left me able to walk maybe a block at the most."

(from Personal Questionnaire)



Disability affects people of all ages and from all backgrounds.

Gender and Age

Males and females in the NWT are equally as likely to have disability.

Elderly people are more likely than any other age group to have disability. The *1994 National Population Health Survey* found that elderly people in the NWT are:

- four times more likely to have disability than persons 45 to 64 years of age.
- twice as likely to have a disability than other Canadian seniors.

Place of Residence

This Assessment found that:

- compared to children and adults (less than 65 years of age), elderly persons with disability are least likely to live and be cared for in a family home.
- persons with disability not living in a family home, live in an institution such as an extended care facility, live alone or live with non-family members.

This Assessment found that:

- non-Aboriginal and Aboriginal persons with disability living in Yellowknife and Hay River likely were not born in these communities/ regions.
- regardless of ancestry or place of birth, 96% of persons with disability consider their home to be in the community or region in which they now live.

Ethnicity and Language

Citizens of Aboriginal and non-Aboriginal ancestry comprise roughly an equal portion of the NWT population. NWT communities with mainly Aboriginal populations had better participation in this Assessment than communities with large populations of non-Aboriginal people. This is one reason that:

- 79% of persons with disability participating in this Assessment have Aboriginal ancestry.

Another reason for the large portion of Aboriginal persons with disability is due to a higher rate of disability among Aboriginal people.

- The *1991 Aboriginal Peoples Survey* reported that 27% of persons with Aboriginal ancestry in the NWT have disability, more than twice the rate of disability within the whole population.

"(I am) very lonely."

(from Personal Questionnaire)

The NWT has eight official languages. Six of these are Aboriginal languages.

This Needs Assessment found that:

- 24% of persons with disability understand another language better than English.
- Dogrib and Slavey are the best understood Aboriginal languages.

Marital Status and Dependents

Adults with disability are unlikely to be in a marital relationship. This Needs Assessment found that:

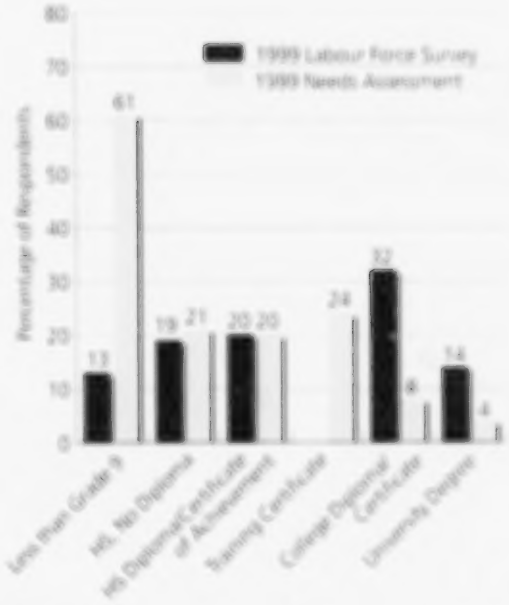
- 67% of persons with disability 15 or more years of age are single, divorced/separated or widowed.
- 44% have someone depending on them for food/shelter/clothing.
- 22% have three or more dependents.
- An equal proportion of males and females with disability have dependents.

Education, Employment and Income

The *1999 NWT Labour Force Survey* reported that 13% of the whole NWT population and 26% of the Aboriginal population 15 years of age and older have less than grade nine education. Less than grade nine education is used in the NWT to describe illiteracy. In this Assessment:

- 61% of persons with disability 15 or more years of age have less than grade nine education. (Figure 3)
- 44% of persons with disability 15-59 years of age have less than grade nine.
- persons 40 to 59 years of age have the highest level of education compared to other adults with disability.
- more than half (58%) of persons with disability 25-39 years of age and 60+ years (57%) have not achieved grade nine.

Figure 3: Formal Education of Adults with Disability Participating in the Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey



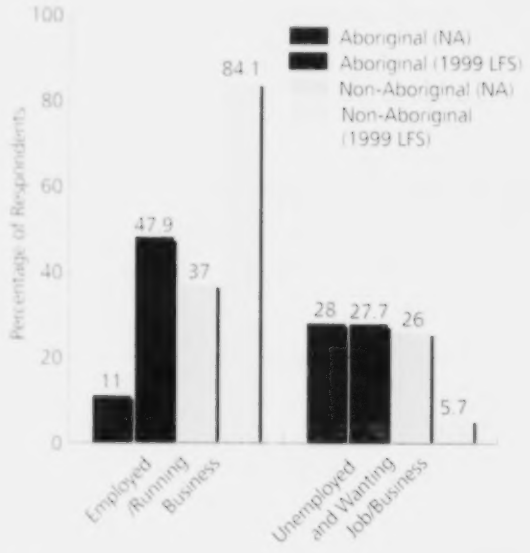
Note:
1. Percentages do not total 100% due to multiple responses (eg. less than grade nine and a training certificate).
2. Both the Needs Assessment and the GNWT's 1999 NWT Labour Force Survey consider adults as persons 15+ years of age.

In the NWT, unemployment among adults 15 or more years of age is 13.7% overall and 26.7% among Aboriginal adults. (1999 NWT Labour Force Survey) This Needs Assessment found that:

- 84% of persons 15 or more years of age and 75% of persons 15-64 years are not employed or running a business.
- even fewer persons with disability of Aboriginal ancestry are employed or running a business. (Figure 4)
- among persons with disability who are 15-64 years of age, 46% would like to be employed or running a business but can't due to disability, illness or age.

- disability seems to have a greater effect on the employment activities of non-Aboriginal people than on persons of Aboriginal ancestry. (Figure 4)

Figure 4: Employment Activity among Adults with Disability by Ethnicity, NWT Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey



Note:
LFS = Labour Force Survey, NA = Needs Assessment

Sources:
1999 NWT Labour Force Survey and Needs Assessment of Persons with Disability, 2000

The NWT does not have an established "poverty line", but elsewhere in Canada poverty is having income of less than $20,000 each year. Among adult persons with disability participating in this Needs Assessment:

- 80% have personal incomes of less than $20,000/year.
- 48% have personal incomes of less than $10,000/year.
- 44% live in households with less than $20,000/year in total income.
- 4% have personal incomes of $30,000-40,000/year, a range that is similar to the average NWT personal income of $33,712. (Bureau of Statistics)
- 16% have personal incomes of more than $40,000/year.

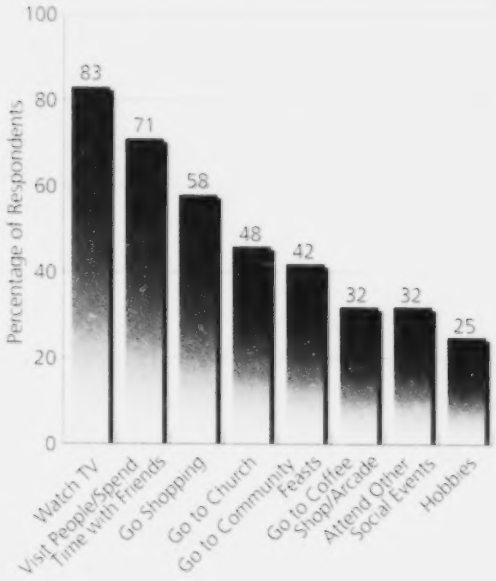
Work, Home, School, Social, Recreation and Leisure Activities

Of the 807 persons with disability participating in this Assessment:

- 68% described their work, home, and/or school activities.
- 88% described social, recreation and leisure activities.

People who did not describe these activities may not be engaged in these daily activities.

Figure 5: Daily Social, Recreation and Leisure Activities of Persons with Disability by Percent, NWT Needs Assessment 2000



Note:
N (Number of Respondents) = 710

This Assessment found that:

- adults and elderly persons with disability are mainly engaged in work in the home including sewing or harvesting/land-based activities.
- 96% of children of school age go to school full or part-time or attend a supervised day program.

Recreation, fitness, sports and active living add to life expectancy, physical and mental health, and overall well-being and quality of life. Only two-fifths (40%) of adults in the NWT are considered to be active enough for optimal public health benefits. (GNWT Municipal and Community Affairs, 2000) This Assessment found that the main social, recreation and leisure activities of persons with disability in the NWT are:

- watching TV (83%); and
- visiting or spending time with people (71%). (Figure 5)

In the NWT, persons with disability may not enjoy the same quality of life as other members of society. Lack of money, loneliness, and poor self-esteem are the main problems affecting the quality of life. (Figures 6 and 7)

"(I am) unable to attend special cultural gatherings. (I) would like assistance to attend youth conferences, treaty gatherings, etc."

(from Personal Questionnaire)

Figure 6: Main Problems Faced in Daily Living by Age, NWT Needs Assessment 2000

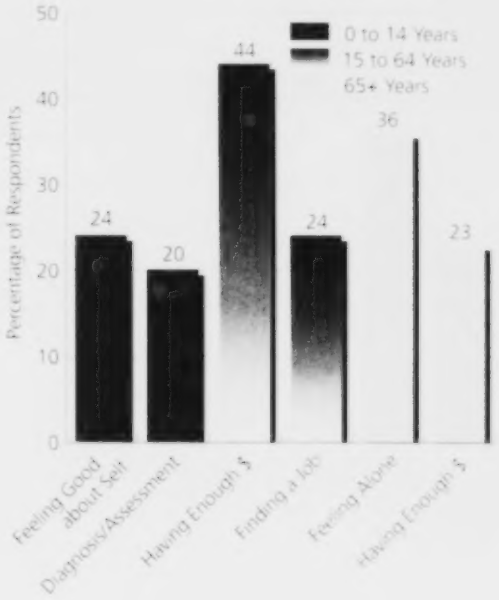
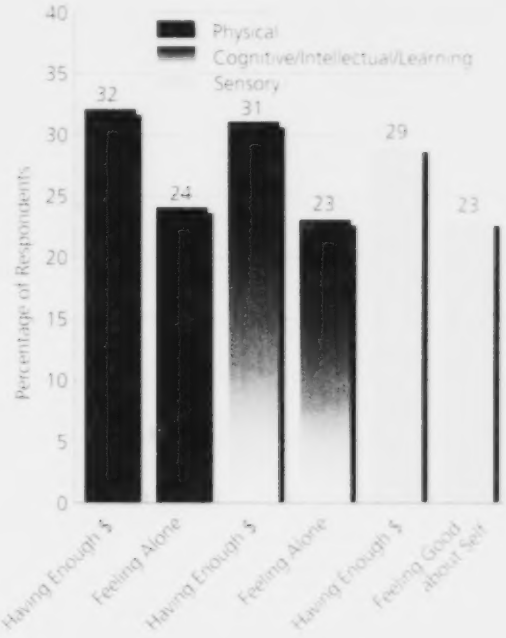


Figure 7: Main Problems Faced in Daily Living by Type of Disability, NWT Needs Assessment 2000



5. Aids and Supports

Aids/equipment (or assistive devices) and supports (including classroom aides) may help persons with disability to overcome limitations in daily living activities, live independently and live with dignity. The use and need for special aids or supports may be affected by:

- understanding of the disability.
- living and lifestyle activities and circumstances.
- awareness of or access to aids or supports.
- attitudes toward disability.

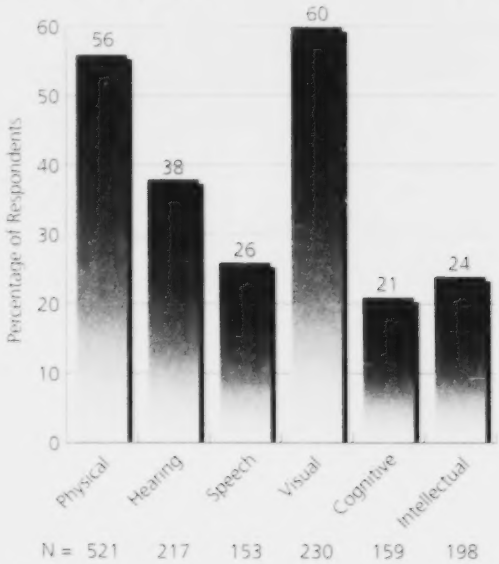
This Needs Assessment heard mainly from adults with known moderate to severe disability who do not work outside the home. This Assessment found that persons with:

- physical and visual disability use special aids and supports more than persons with other types of disability. (Figure 8)
- cognitive disability are least likely to use special aids or supports.
- physical or sensory disability use the most extensive range of special aids or supports.

Some persons with disability may use a special aid or support but also need the same aid/ support. For example, some people using a hearing aid now also need a hearing aid. Malfunctioning or inappropriate aids/supports may be the reason that people say they need aids/support that they already have. This Assessment found that persons with:

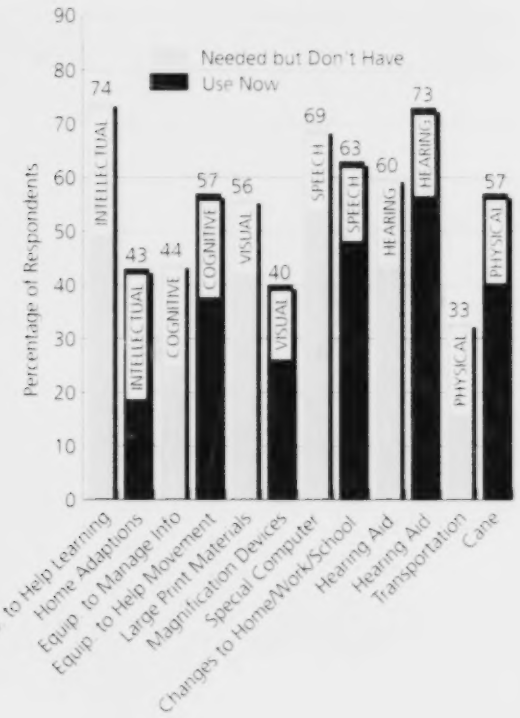
- speech disability have a great need for special computer equipment and software. (Figure 9)
- visual disability have a particular need for large print materials.
- intellectual disability mainly need equipment to help learning.

Figure 8: Use of Special Aids/Equipment/ Supports by Type of Disability, NWT Needs Assessment 2000



Note:
1. Data were not collected from persons with learning disabilities.
2. N = Number of Respondents

Figure 9: Main Special Aids/Equipment/ Supports Used and Needed by Type of Disability, NWT Needs Assessment 2000



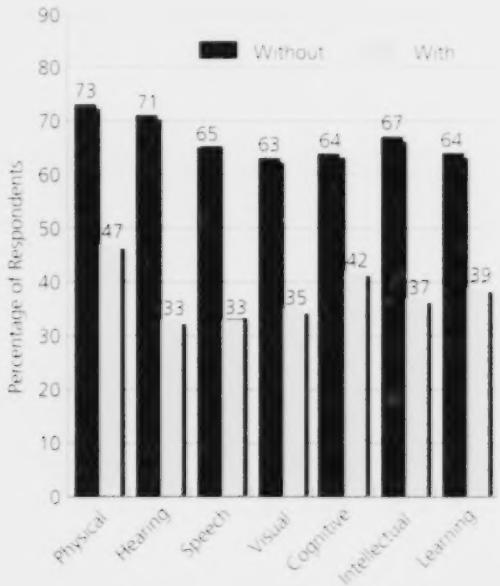
Note:
Special aids/equipment/supports for learning disabilities were not investigated.

Actions taken to care for ourselves and participate with others are typically understood as the usual activities of daily living. Persons with disability in the NWT have fewer difficulties in the activities of daily living with the use of special equipment/aids/supports. (Figure 10)

"(She was) offered a hearing aid but they wanted her to pay over $400, couldn't afford to pay for it and was having difficulty using – it kept falling out/off and her hands are too stiff to put it back in."

(from Parent/Caregiver Questionnaire)

Figure 10: Difficulties Encountered With and Without the Use of Special Equipment/Aids/ Supports by Frequency, NWT Needs Assessment 2000



Both with and without special aids and supports, persons with disability in the NWT are limited in their participation with others and in their ability to care for themselves. This Needs Assessment found that:

- physical disability creates difficulties lifting, carrying, moving, standing and walking.
- visual disability creates reading difficulties.
- hearing disability excludes persons from verbal communications and limits understanding.
- persons with cognitive, intellectual or learning disabilities are limited in their understanding and participation in the home, work, school and community environments, and have difficulty caring for themselves.

6. Use and Need for Programs and Services

The need and use of programs and services depends on the severity of disability and the awareness and availability of supports/ assistance. This Needs Assessment found that:

- the current demand for programs/services by persons with disability exceeds the availability and/or the capacity of existing programs/services.
- there are nearly as many people with disability who still need services as there are people receiving them now.
- programs/services in greatest demand are rehabilitation, assessment, specialized/ individualized intervention, alternative treatment, financial assistance and advocacy/ information.
- programs/services unable to meet the demand today will not be able to cope with expected increases in demand in the future.

The main programs and services used and needed now (but not received now) by persons with disability in the NWT are shown in Table 3.

Medical Health Services

Chronic pain or discomfort are faced daily by many persons with disability. Medical health services are available in some form in every NWT community. They are the most widely used of all services among persons with disability in the NWT.

- General medical care/treatment and testing/ diagnostic/assessment services have the greatest use.
- These programs/services together with Occupational and Physical Therapy and home/personal care services, will be needed the most in the future.

Community service providers say that there are not enough staff to serve persons affected by disability who need or want occupational therapy or physiotherapy, speech/language pathology/development, and alternative therapy/treatment.

Social and Mental Health Supports

Low self-esteem, loneliness and lack of support are among the problems which cause persons with disability to seek social and mental health supports. Most NWT communities offer these supports through a government agency(ies), First Nation or a community organization.

- Personal supports such as local support groups, are used the most now by persons with disability.
- Special aids, equipment and tools are the greatest unmet needs among persons with disability. Workshops and resource materials are examples of special aids/tools needed.
- The current need for addictions counselling/ treatment services and alternative therapy exceeds present use.

Table 3: The Number of NWT Persons with Moderate to Severe Disability Using Services Now, Needing Services and Not Getting Them Now by Main Type of Program/Service, 2000 and Expected Demand in 2004 and 2009

Program/Service	Use Now	Needed Now and Not Getting	Total 2000 Demand N=1,780	Total 2004 Demand N=1,982	Total 2009 Demand N=2,276
Medical Health Services					
General Medical	1,194	141	1,335	1,487	1,707
Testing	1,026	198	1,224	1,368	1,570
Social and Mental Health					
Personal supports	531	249	780	872	1,001
Special aids	393	303	696	773	888
Accommodation/Housing					
Subsidy/Money	330	252	582	654	751
Income					
Income support	501	219	720	793	910
Life Skills, Employment and Residential					
Personal/FamilySupport	189	159	348	396	455
In-Home Support	156	159	315	357	410
Education and Training for Adults					
Academic Upgrading	126	199	324	357	410
Job Training	114	168	282	317	364
Other Programs/Services					
Transportation	324	324	648	714	819
Advocacy to get Services	216	255	417	515	592

Note:
1. *N = Number of Respondents*
2. *This Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability in the NWT. The demand for 2000 is three times the amount that was identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.*

Table 3: The Number of NWT Persons with Moderate to Severe Disability Using Services Now, Needing Services and Not Getting Them Now by Main Type of Program/Service, 2000 and Expected Demand in 2004 and 2009

Program/Service	Use Now	Needed Now and Not Getting	Total 2000 Demand N=1,780	Total 2004 Demand N=1,982	Total 2009 Demand N=2,276
Medical Health Services					
General Medical	1,194	141	1,335	1,487	1,707
Testing	1,026	198	1,224	1,368	1,570
Social and Mental Health					
Personal supports	531	249	780	872	1,001
Special aids	393	303	696	773	888
Accommodation/Housing					
Subsidy/Money	330	252	582	654	751
Income					
Income support	501	219	720	793	910
Life Skills, Employment and Residential					
Personal/FamilySupport	189	159	348	396	455
In-Home Support	156	159	315	357	410
Education and Training for Adults					
Academic Upgrading	126	199	324	357	410
Job Training	114	168	282	317	364
Other Programs/Services					
Transportation	324	324	648	714	819
Advocacy to get Services	216	255	417	515	592

Note:
1. N = Number of Respondents
2. This Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability in the NWT. The demand for 2000 is three times the amount that was identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Community service providers see the current demand for psychological or psychiatric help and alternative therapy/treatment as much greater than the capacity of staff to deliver these services.

Accommodation/Housing Services

Accommodation/housing services are available in every community in the NWT, mainly through local housing organizations or municipal/First Nation governments.

- Housing subsidies are used and needed now among persons with disabilities.
- The need for help fixing or adapting the home is more than double the current use of these services.

Income

Persons with moderate to severe disability have personal/household incomes that are below the national poverty line.

- The main problem persons with disability face is not having enough money.
- Next to medical and social/mental health services, income support is in the greatest demand by persons with disability.
- Persons with disability also need financial assistance and advice

"I have to fly out of town to get services."

(from Personal Questionnaire)

Life Skills, Employment and Residential Supports

Opportunities to secure a job and have enough money to live independently and with dignity are limited, particularly when:

- 61% of adults with moderate to severe disability have less than grade nine education.
- 84% are unemployed.
- aids and supports are needed to participate in daily living activities at home, work, school and in the community.

Compared to medical and social services, few persons with disability use life skills, employment and/or residential supports. Unavailability of these services in smaller NWT communities may be the reason for this. Overall, the need for these services is as great as or greater than current use.

Community service providers say that there are not enough staff to meet the current demand for paid residential support.

Education and Training for Adults

Aurora College Community Learning Centres operate in 11 NWT communities. Few other organizations in the NWT offer adult literacy and basic education programs.

- Education/academic upgrading and job training are in demand by persons with disability.
- The need now for education/academic upgrading is greater than current use (126 people compared to 198).

Community service providers say that adult-focused education and training programs and services are severely understaffed to meet the demand.

Education and Training for Children

This Needs Assessment provides limited information on children with disability. An assessment of student needs in NWT classrooms undertaken by the GNWT Department of Education, Culture and Employment will provide more comprehensive information on program and services needs among this segment of the population.

Legal and Protection Services

The GNWT identifies brain-related disabilities (eg. cognitive, intellectual and learning) as one of the reasons that children/youth come into care or into the legal system. Mediation, negotiation and advocacy are the main legal services used and needed by persons with disability. Emergency care and shelter are the main protection services needed. In this Assessment, protection and legal services were the categories of services with the lowest use and unmet need.

Information, Advocacy and Other Programs and Services

A variety of other programs and services for persons with disability are available in some NWT communities.

- Guardian/trusteeship or supported decision-making, transportation services, and general information/referral/support services have the greatest use now among persons with disability.
- The greatest unmet need is for transportation, advocacy and disability awareness/education services.

Community service providers believe that information, advocacy, transportation, communications and respite programs/service that may be available in some communities, are not staffed adequately to meet the demand for these services.

Almost two-thirds of persons with disability (62%) believe that programs and services do not meet their needs. There are four main reasons for this:

1. General lack of understanding, support and recognition of disabilities.
2. Lack of awareness and sensitivity toward Aboriginal languages/customs.
3. Lack of access to service in the (home) community.
4. Lack of care and attention by community and service providers.

"We need more programs and service HERE."

(from Personal Questionnaire)

"Not being able to participate in a group discussion or conversation, because not able to hear everyone else's comments, leaves a person feeling left out and makes you wonder if people question your intelligence. Tend to avoid groups or gatherings of more than a couple of people."

(from Personal Questionnaire)

7. Caregivers

This Needs Assessment heard from parents and other caregivers who are not paid to care for persons with disability.

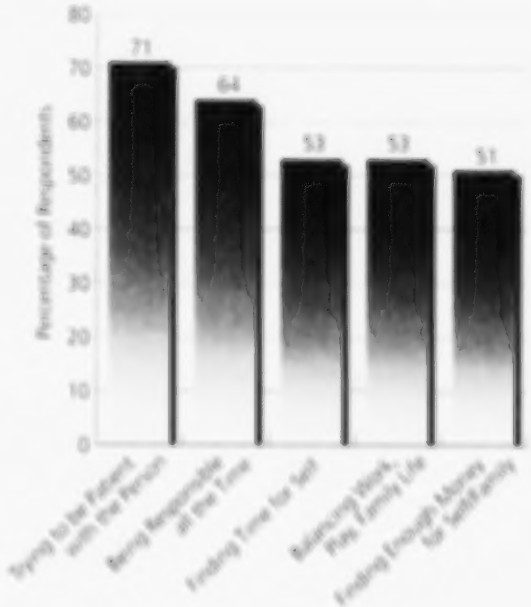
- 87% care for persons with moderate to severe disability.
- 57% care for a male child or adult (younger than 65 years of age).
- 71% care for people whose disability has been assessed, diagnosed or named by a professional.
- Caregivers say that physical disability is most likely to have been diagnosed/named while cognitive disability is least likely to be known.
- 37% care for persons with multiple disabilities.
- 49% provide 24-hour care/supervision.

Parents/caregivers were asked to describe the main behaviours/characteristics of the disability of the person they care for. Most often they identified difficulty with and/or loss of:

- ability to move quickly or easily.
- strength or ability to hold/lift things.
- understanding words/verbal comprehension, remembering, learning new things.
- controlling emotions (eg. anger, fear).
- focussing or paying attention.
- writing, spelling and reading.

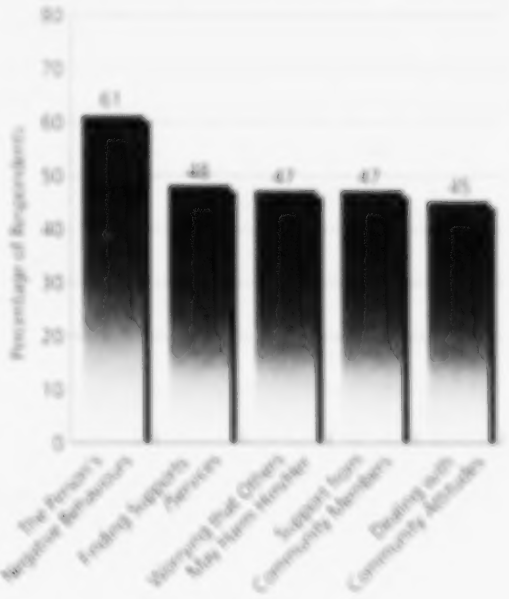
Parents/caregivers face tremendous challenges. The main personal challenges are being patient and responsible all of the time. (Figure 11) Dealing with negative behaviours is the main challenge to providing care and support. (Figure 12) Respite, caregiver training and support services would help caregivers to cope with these challenges.

Figure 11: Personal Challenges Faced by Parents/Caregivers, NWT Needs Assessment 2000



Note:
N (Number of Respondents) = 217

Figure 12: Other Challenges Faced by Parents/ Caregivers, NWT Needs Assessment 2000



Note
N (Number of Respondents) = 195

Giving and receiving love from the person they care for are among the greatest rewards for parents/caregivers of persons with disability. (Figure 13)

Parents/caregivers of persons with disability use a variety of programs/services to help them to give care. Special equipment/supports and transportation to get to appointments are two of the services most frequently used. (Figure 14)

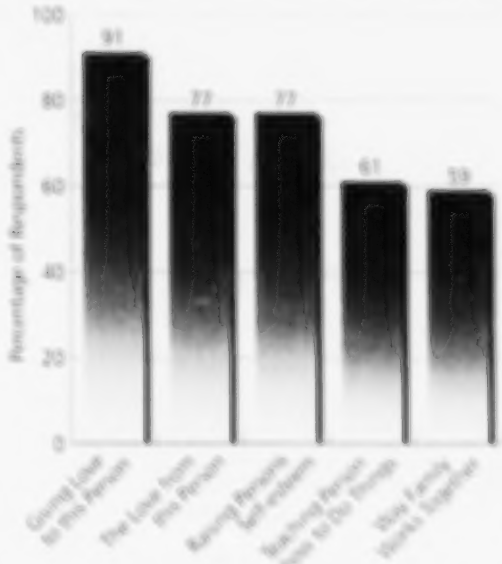
"My child faces problems at school – fighting with peers at school, teasing and bothering her."

(from Personal Questionnaire)

To help them to give care, parents/caregivers of persons with disability identify a range of unmet needs.

- They need information, understanding, support and financial resources the most. (Figure 15)
- These needs may be met through respite, counselling, advocacy and caregiver benefit programs.

Figure 13: "Good" Things about Caring for Persons with Disability by Percent of Parents/ Caregivers, NWT Needs Assessment 2000

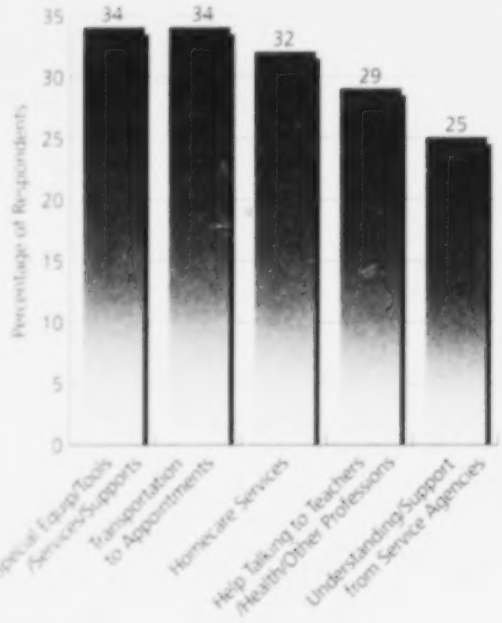


Note
N (Number of Respondents) = 218

"No one asks me what I need."

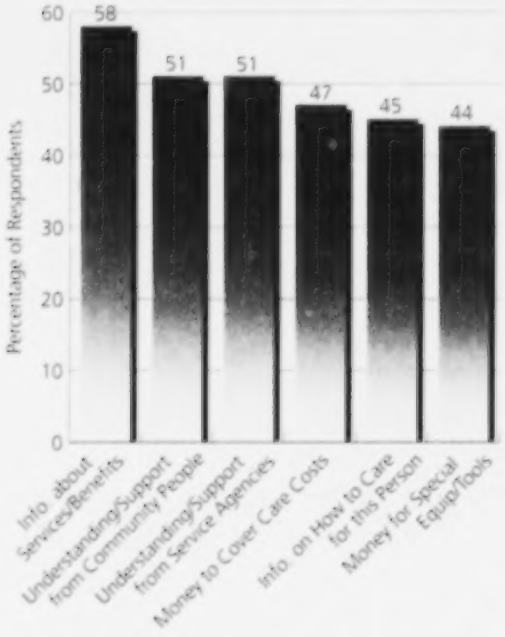
(from Personal Questionnaire)

Figure 14: Programs and Services Used by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000



Note:
N (Number of Respondents) = 158

Figure 15: Programs and Services Needed by Parents/Caregivers of Persons with Disability Participating in the Needs Assessment,2000



Note:
N (Number of Respondents) = 185

"I want to have dry meat, see moose and go fishing but can't."

(from Personal Questionnaire)

"(There is) no funding what-so-ever to raise a learning disabled child!"

(from Personal Questionnaire)

8. Programs and Services – Best Practices

Community service providers listed the challenges they face in delivering programs/services to meet the needs of persons affected by disability as:

- access to qualified staff.
- appropriate materials.
- adequate financial resources.
- limited awareness/support for disability in the community.

Other barriers are high staff turnover, poor understanding of disabilities, and poor collaboration and information sharing among service providers. These same circumstances also created difficulties completing this Needs Assessment.

People in the NWT with disabilities describe five main ingredients of the programs/services which meet their needs as:

1. giving a sense of peace and security about/within their environment.
2. support to participate in community events, particularly cultural activities.
3. access to country foods and help with such activities as sewing, drying meat and getting ice.
4. receiving services in one's own community.
5. receiving services in Aboriginal languages.

This Assessment identified appropriate programs/services for persons affected by disability as those focussing on:

1. Collaboration to advocate for persons and parent/caregivers affected by disability.
2. Outreach to persons affected by disability to provide relief from isolation and loneliness.
3. Physical and intellectual stimulation for persons with disability to enhance capacity to participate in and contribute to the community.
4. Early intervention to detect and develop skills/techniques to cope with disability.
5. Rehabilitation services and tools to help manage daily living activities.
6. Respite and supports for caregivers.
7. Transportation services and adaptations to facilitate access in the community.

"(I) would appreciate more traditional food and more people who could speak in my language."

(from Personal Questionnaire)

9. Taking Action

Many of the people affected by disability participating in this Needs Assessment doubt the will of government, other organizations, communities, families and individuals to address disability issues. Taking action from this Needs Assessment will demonstrate this will. It is recommended that:

1. The partners sponsoring this Needs Assessment of Persons with Disabilities in the NWT, use the findings to plan appropriate programs and services for people in the NWT affected by disability.
2. The partnership established for this Needs Assessment continue in order to ensure that appropriate programs and services for people in the NWT affected by disability are implemented.
3. The partnership established for this Needs Assessment communicate the findings and intended actions to the general public.
4. Responsibility for disability issues within the Government of the NWT be clearly identified and communicated to the public.
5. Those factors limiting collaboration in this Needs Assessment be addressed by the partners both in the example that they set and the message they send to service providers and organizations delivering programs/services/supports to persons affected by disability.
6. The partners begin discussions with the GNWT Department of Education, Culture and Employment to identify complementary approaches to addressing the needs of children/youth with disability and their parents/caregivers, as identified in this Needs Assessment and the Department's Student Needs Survey.
7. Lessons learned from this Assessment be applied to Phase 2 research into psychiatric disabilities.

"I don't know what my personal income is or how that is defined in a subsistence lifestyle."

(from Personal Questionnaire)

A partnership of:

Canada
Northwest Territories

Canada
Territoires du Nord-Ouest

Service Centre / Centre de services

Northwest Territories Health and Social Services

Human Resources Development Canada

Développement des ressources humaines Canada

Yellowknife Association for Community Living

Somba k'è dọne nàde xè eghàtagìde

YWCA

N.W.T. COUNCIL FOR DISABLED PERSONS

MaryAnne Duchesne

Living with Disability... Living with Dignity

Needs Assessment of Persons with Disabilities in the NWT – **Findings Report**

Living with Disability.....Living with Dignity

Needs Assessment of Persons with Disabilities in the NWT - Findings Report

Final Report

Research conducted by Lois Little, Sandy Auchterlonie and
Bob Stephen, Lutra Associates Ltd.
on behalf of the partnership of:

- NWT Council for Disabled Persons
- GNWT Health and Social Services
- Yellowknife Association for Community Living
- GNWT Education, Culture and Employment (College and Careers Division)
- YWCA of Yellowknife
- Human Resources Development Canada
- MaryAnne Duchesne

July 2000

Needs Assessment of Persons with Disabilities in the NWT - Findings

Table of Contents **Page**

Acknowledgments

Executive Summary i

1. An Introduction to the Needs Assessment of Persons with Disabilities 1
1.1 An Overview 1
1.2 Objectives and Parameters 2
1.3 Needs Assessment Methodology 3
1.4 Participation 7
1.5 Other Research on Disability in the NWT 10
1.6 Validity of the Needs Assessment 17
1.7 Projections of the NWT Population with Disability 21
1.8 Research Notes 21

2. People with Disabilities in the NWT 24
2.1 An Introduction to People with Disability 24
-Gender 24
-Ethnicity and Language 25
-Residency and Care 27
-Marital Status and Dependents 29
-Education, Employment and Income 30
2.2 Describing Disability 34
-Type of Disability 34
-Severity and Assessment of Disability 38

3. Living with Disability 46
3.1 Use of and Need for Special Aids/Equipment and Support 46
3.2 Living with Various Types of Disability 49
-Physical Disability 50
-Hearing Disability 52
-Speech Disability 53
-Visual Disability 55
-Cognitive, Intellectual and Learning Disabilities 56
3.3 Work, Home, School, Recreation and Leisure Activities 59

3.4 The Major Challenges of Living with Disability 62
3.5 Parent/Caregiver Perspectives on Living with Disability 65

4. Programs and Services 69
4.1 Current and Future Program/Service Needs Among Persons with Disability in the NWT 70
-Medical/Physical Health Services 71
-Social and Mental Health Service 73
-Accommodation/Housing Services 76
-Income 78
-Life Skills, Employment and Residential Supports 79
-Education and Training for Adults 81
-Education and Training for Children and Youth 83
-Legal Services 85
-Protection Services 86
-Other Programs and Services 87
4.2 Program/Service Needs of Parent/Caregivers of Persons with Disability 89
4.3 Delivering Appropriate Programs and Services to Persons Affected by Disability 92
4.4 Programs and Services Best Practices 97

5. Recommendations to the Needs Assessment Partners 99

Tables

1: Regional/Community Participation in the NWT Needs Assessment, 2000 7
2: The NWT/Nunavut Population with Disability by Percent and Age, 1986, 1991 and 1996 11
3: Percent of the NWT Population 12 Years of Age and Older Reporting a Disability by Age, 1994 12
4: Distribution of the NWT Population in 1999 and NWT Needs Assessment Respondents with Disability by Age, 2000 18
5: Severity of Disability by Percent of the NWT Population Reporting Disability in 1999 and in the 2000 NWT Needs Assessment (as a Percent of the NWT Population with Disability) 20
6: Projected Number of Persons Living in Households in the NWT with Disability by Severity, 1999-2019 21
7: Number of Persons Born and Residing in NWT Regions by Current Residence and Ethnicity, NWT Needs Assessment 2000 28
8: Family Circumstances of Persons with Disability 15 or More Years of Age by Percent, NWT Needs Assessment 2000 30
9: Education of Persons with Disability by Age, NWT Needs Assessment 2000 32
10: 1991, 1994 and 2000 Percent of the NWT Population with Disability by Type 36
11: The Nature of Disability by Age, 1991 Health and Activity Limitation Survey for NWT/Nunavut and the NWT Needs Assessment 2000 37
12: A Self-Assessment of Disability by Persons with Disabilities, NWT Needs Assessment, 2000 42
13: Severity of Disability by Age of Persons with Disabilities, NWT Needs Assessment 2000 Compared to the Estimated NWT Population with Disability in 1999 42
14: The Reported Reasons for Disability by Percent of Persons with Disability, NWT Needs Assessment 2000 44
15: Reported Difficulties with Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Physical Disabilities, NWT Needs Assessment 2000 50
16: Number of Persons with Physical Disability Who Use and Need Special Aids/ Equipment/Support, NWT Needs Assessment 2000 51
17: Reported Difficulties with Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Hearing Disabilities, NWT Needs Assessment 2000 52
18: Number of Persons with Hearing Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000 53
19: Reported Difficulties with Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Speech Disabilities, NWT Needs Assessment 2000 54
20: Number of Persons with Speech Disability Who Use and Need Special Aids/ Equipment/Support, NWT Needs Assessment 2000 54
21: Reported Difficulties with Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Visual Disabilities, NWT Needs Assessment 2000 55

22: Number of Persons with Visual Disability Who Use and Need Special Aids/ Equipment/Support, NWT Needs Assessment 2000 56
23: Daily Living Activities Difficult With and Without the Use of Special Equipment/ Aids/Support for Persons with Cognitive, Intellectual and Learning Disabilities, NWT Needs Assessment 2000 57
24: Number of Persons with Cognitive or Intellectual Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000 58
25: The NWT Demand for Medical/Physical Health Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 72
26: The NWT Demand for Social and Mental Health Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 75
27: The NWT Demand for Accommodation/Housing Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 76
28: The NWT Demand for Financial Assistance in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 79
29: The NWT Demand for Life Skills, Employment and Residential Supports in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 81
30: The NWT Demand for Education and Training Services in 2000, 2004 and 2009 by Number of Adults with Moderate to Severe Disability 82
31: The NWT Demand for Education and Training Services in 2000, 2004 and 2009 by Number of Children/Youth with Moderate to Severe Disability 84
32: The NWT Demand for Legal Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 85
33: The NWT Demand for Protection Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 87
34: The NWT Demand for Other Programs and Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability 88

Figures

1: Persons with Disability by Age, NWT Needs Assessment 2000 19
2: Gender of Persons by Type of Disability and Percent, NWT Needs Assessment 2000 25
3: Ethnicity of Persons with Disability, NWT Needs Assessment 2000 Compared to the 1996 Census 26
4: Language Understood Best by Percent of Persons with Disability, NWT Needs Assessment 2000 27
5: Place of Residence of Persons with Disability, NWT Needs Assessment 2000 29
6: Formal Education of Adults with Disability in the NWT Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey 31
7: Employment Activity of Adults by Level of Education, NWT Needs Assessment 2000 32
8: Personal and Household Income Levels by Percent of Respondents, NWT Needs Assessment 2000 34
9: Type of Disability by Percent, NWT Needs Assessment 2000 35

10: Diagnosed and Assessed Disability (including those named by a professional) by Percent of Parents/Caregivers Caring for Persons with Disabilities, NWT Needs Assessment 2000 39
11: Percent of Persons Having an Assessed/Diagnosed/Named Disability, NWT Needs Assessment 2000 40
12: Self-Assessment of the Future Condition of Disability by Percent, NWT Needs Assessment 2000 43
13: The Main Reported Reason for Disability by Percent of Persons with Disability, NWT Needs Assessment 2000 45
14: Use of Special Aids/Equipment/Support to Help Cope with Disability by Percent of respondents, NWT Needs Assessment 2000 47
15: Reported Difficulties Encountered With and Without the Use of Special Equipment/Aids/Supports by Frequency, NWT Needs Assessment 2000 48
16: Main Special Aids/Equipment/Support Used and Needed by Type of Disability, NWT Needs Assessment 2000 49
17: Daily Activities at Work, Home and/or School by Percent of Persons with Disability, NWT Needs Assessment 2000 59
18: Daily Social, Recreation and Leisure Activities by Percent of Persons with Disability, NWT Needs Assessment 2000 60
19: Main Problems Faced in Daily Living by Age and Percent, NWT Needs Assessment 2000 62
20: Main Problems Faced in Daily Living by Type and Percent, NWT Needs Assessment 2000 63
21: Type of Disability of Person Cared for by Percent of Parents/Caregivers, NWT Needs Assessment 2000 66
22: Personal Challenges Faced by Parents/Caregivers of Persons with Disabilities, NWT Needs Assessment 2000 67
23: Other Challenges Faced by Parents/Caregivers of Persons with Disabilities, NWT Needs Assessment 2000 67
24: "Good" Things About Caring for Persons with Disability by Percent of Parents/ Caregivers, NWT Needs Assessment 2000 68
25: Programs and Services Used by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000 91
26: Programs and Services Needed by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000 92
27: Information Sharing on Disability Issues and Needs by Percent of Community Service Providers, NWT Needs Assessment 2000 95

Appendices:

A: Terms of Reference
B: Needs Assessment of Persons with Disability Chronology
C: Needs Assessment Questionnaires and Newsletter
D: Community Team Members
E: Bibliography
F: Generalizing the Results of the Needs Assessment to the Total NWT Population with Disability

Acknowledgments

This study was made possible by the contributions of the partners who sponsored this Needs Assessment and the many individuals affected by disability throughout the NWT. The research team from Lutra Associates Ltd. wishes to acknowledge the particularly strong commitment and dedication of the following individuals. These people worked very hard to ensure the success of this study. Lois Little, Sandy Auchterlonie and Bob Stephen at Lutra Associates want to thank the following people for enabling the voices of persons with disabilities to be heard:

Marlene Wolki, Bill Kudluk and Trudy McClements, Paulatuk
Alice Kimiksana, Barbara Memogana and Tony Kulbisky, Holman
Shirley Esau and Lorna Dillon, Sachs Harbour
Lucy Dillon and Vera Ovayak, Tuktoyaktuk
Wendy Mepham and Barb Lennie, Inuvik
Kim McLeod, Jackie Ryan, and Edna Alexi, Fort McPherson
Carol Norwegian, Courtnae Clark and Corrine Dillon, Tsiigehtchic
Gladys Edwards, Diane Gordon and Shauna Gordon, Aklavik
Sharon Tutcho, Colville Lake
Phoebe McNeeley, Fort Good Hope
Andrea Dougherty, Elaine Doctor and Lillian Doctor, Tulita
Tony Harrison, Norman Wells
Carolyn Yukon, Deline
Leah Keats, Fort Simpson
Faye Stark and Leonie Sabourin, Fort Providence
Susan Kotchea, Bernice Hardisty and Marie Kotchea, Fort Liard
Noleen Villebrun, Fort Resolution
Betty Lyons, Hay River
Sharon Sunrise and Rita Plunkett, Hay River Reserve
Sister Agnes Sutherland, Pamela Bradley and Sylvie Tordiff, Fort Smith
Linda McConnell, Alestine Mantla and Rachel Ann Liske, Rae-Edzo
Mary Jane Tsetta, Ndilo
Aggie Brockman,Vita Morin, Jeff Miniely, Sue Edmonds, and Donna Allen, Yellowknife
Helene Usherwood, Christina Vernon, Jan Stirling and Barb Beaton, Yellowknife
Doreen Ann Apple, Rae Lakes
Etonia Hardisty, Wrigley
Lucy Simon, Jean Marie River
Ruby Jumbo and Brenda Jumbo, Trout Lake

The research team at Lutra Associates would also like to thank the people on the Disabilities Needs Assessment Project Working Group who were diligent in their representation of the interests of their organizations, members and clients in the research.

Aggie Brockman, NWT Council for Disabled Persons
Miriam Wideman and Lani Cooke, Yellowknife Association for Community Living
Kate Tymstra, YWCA
MaryAnne Duchesne, self-advocate
Bernie Karpan, Mary-Jane Stewart, Cecily Hewitt, and Angus MacKay, GNWT Health and Social Services
Wendy McPherson and Angela Ballard, GNWT Education, Culture and Employment (College and Careers Division)
Barbara Deakin, Metis Nation of the NWT
Thomas Shepherd, Human Resources Development Canada

EXECUTIVE SUMMARY

A disability is any degree of physical, sensory, psychiatric, cognitive, intellectual or learning limitation which causes difficulty in the usual activities of daily living. Approximately 13% of the NWT population have a disability. Based on 1999 population estimates, this means that there are 5,453 people with disability in the NWT.

This Needs Assessment of Persons with Disabilities in the NWT was undertaken to determine the nature and distribution of disabilities within the NWT population, and the gaps in, and future requirements for services among this population.

This Assessment was undertaken by a unique, multi-sector partnership involving two levels of government, territorial and community-based non-government organizations, a self-advocate and a First Nation organization. The voices of almost 1260 NWT people are reflected in this Assessment and 807 of these are people with disability. Parents/caregivers (227), community service providers (181) and regional program managers (44) are the other voices heard in this Assessment.

This Needs Assessment collected sufficient information to make statements about the whole NWT population with moderate to severe disability. The number of persons with moderate to severe disability not living in institutions in the NWT is 1,779. The remaining 3,674 NWT persons with disability have a mild degree of disability. This Needs Assessment did not hear from persons with mild disability, perhaps because they do not acknowledge disability or do not need help in daily living activities. The Needs Assessment also did not hear from many children (0-14 years) with disability and therefore adds little to the poor state of knowledge about NWT children with disability.

This Needs Assessment provides information on five disabilities - physical, sensory, cognitive, intellectual and learning - as well as some information on psychiatric disability.

People with Disability in the NWT

Males and females are equally as likely to have disability. People of Aboriginal ancestry in the NWT have a rate of disability that is twice that of the population as

a whole. The prevalence but not necessarily the severity of disability increases with age.

Over three-quarters of NWT persons with moderate to severe disability understand English the best. Those who understand another language better than English are likely to be Dogrib or Slavey speakers.

Most persons with moderate to severe disability live in a family environment. Compared to other persons with disability, elderly people with disability are most likely to live alone and to feel alone.

People with disability 15 or more years of age are unlikely to be in a marital relationship but 44% have dependents. This same age group has low literacy levels (61% have less than grade 9 education). Among the small number of persons with disability with grade 12 or more education, the employment rate is 10 times that of persons with less than grade 9. Only one-quarter of persons with disability 15-59 years of age and 16% of all persons with disability 15 or more years of age, are employed or run a business. Low education and poor employment circumstances are the main reasons that 80% of working age and elderly persons with disability have personal incomes of less than $20,000/yr. Almost half (48%) earn less than $10,000/yr. Over half of persons with disability 15 or more years of age use, need or will need income support. Insufficient financial resources is the most pressing problem faced by adults with disability.

Type, Severity and Assessment of Disability

The main reasons for disability in the NWT are illness/disease, age or conditions before or at birth.

Sixty percent (60%) of persons with moderate to severe disability in the NWT have multiple disabilities. Within the NWT population with moderate to severe disability:

- 65% have physical disability.
- 32% have learning disability.
- 29% have visual disability.
- 27% have hearing disability.
- 25% have intellectual disability.
- 20% have cognitive disability.
- 19% have speech disability.

- 10% also have psychiatric disability.

NWT front-line workers say that the number of persons with brain-related disability may be conservative given significant and sustained levels of high risk behaviours such as alcohol abuse. These workers also see high risk behaviours as contributing to expected increases in disability in the coming decade.

In this Needs Assessment, the small number of NWT children (0-14) who participated, mainly have learning, intellectual or speech disability. Adults of all ages are more likely to have physical disability than any other disability. The disability of 92% of persons participating in this Needs Assessment has been diagnosed/assessed/named by a professional. About 85% of persons with disability expect that their disability will get worse or they are uncertain about the future condition of their disability.

Living with Disability

Over half of persons with disability (57%) use special aids/equipment/ support in daily living. By using special equipment/aids/supports persons with disability have fewer difficulties in daily living. Without special aids/supports, persons with disability have difficulty participating in their communities, caring for themselves, and living independently and with dignity. Aids/supports are more likely to be used by persons with physical and visual disability than persons with cognitive disability. Awareness or availability of aids/supports are issues for persons with lesser known or brain-related disabilities.

The low level of participation of adults with disability in the work place, in training or education, and in social activities is evident throughout the Needs Assessment. The main social/leisure activity of persons with disability (83%) is watching TV. Less than 13% participate in physical fitness, sport or exercise.

The challenges associated with living with disability are influenced by age. Children with disability have problems feeling good about themselves. Persons 15-64 years of age with disability have problems getting enough money and elderly persons are lonely. Lack of adequate financial resources is the most significant problem facing persons with disability in the NWT. Parents/caregivers of persons with disability also struggle with this problem. They also encounter tremendous difficulty getting professional or community support to fulfill their role

as caregivers.

Programs and Services

The NWT population with moderate to severe disability will continue to grow. An aging population and continued high risk behaviours are the main factors expected to contribute to anticipated increases in the population with disability. Within the context of a growing population with moderate to severe disability,

- the current demand for programs and services exceeds the availability and capacity of existing programs/services.
- nearly as many people still need services as are receiving them now.
- rehabilitation, assessment, individualized intervention, alternative treatment, financial assistance and information programs are needed the most.
- parents/caregivers receive very little assistance/support to give care.
- programs/services unable to meet current demand will be ill-equipped to respond to a growing population with disability.

Delivering appropriate programs/services to persons affected by disability is made difficult by high staff turn over, large caseloads, poor understanding of disability and lack of opportunities to work with other service providers. There are several examples of programs/services in the NWT which meet the needs, including the cultural needs of persons affected by disability. These programs/services are generally not available to persons with disability living in small communities.

It is recommended that the Needs Assessment partners use the research findings to plan appropriate programs and services for persons affected by disability in the NWT.

1. An Introduction to the Needs Assessment of Persons with Disabilities

1.1 Overview

Disability is described by the World Health Organization (WHO) as the "*the loss or reduction of functional ability and activity due to any disturbance of, or interference with, the normal structure and functioning of the body, including the systems of mental function.*" In this Needs Assessment, a more simplified definition was used. **A disability is any degree of physical, sensory, psychiatric, cognitive, intellectual or learning limitation which causes difficulty in the usual activities of daily living.**[1] Persons with disability may experience various degrees of limitation ranging from mild to moderate to severe. Difficulties in usual activities of daily living (eg. taking care of oneself, participating with family, in work/school and in community/social events) may result from limitations caused by more than one disability, for example a physical disability and a learning disability.

The Needs Assessment of Persons with Disabilities determines the nature and distribution of disabilities within the NWT population, and the gaps in services and future service needs of persons affected by disabilities. This Needs Assessment was the first research of its kind to:

- assess the needs of persons with disabilities in the NWT, those who care for them and are not paid to do so, and those who are paid to provide services; and
- be sponsored by a multi-sector partnership with a common interest in disability, and coordinated by a non-government organization.

---

[1]Definitions for each of the five types of disability under investigation in this Needs Assessment are provided in Appendix C. A definition was not developed for psychiatric disability.

This Assessment involved two levels of government, a First Nation organization, territorial and community-based non-government groups, and a self-advocate. The partners functioned as the Disabilities Needs Assessment Project Working Group. The NWT Council for Disabled Persons coordinated the Assessment on behalf of the partners and was the chair of the Working Group. The partners were active in all aspects of this Assessment and worked closely with the research team from Lutra Associates Ltd.

Information collected in the Needs Assessment is presented in this report and a popular summary entitled **Living with Disability.....Living with Dignity Needs Assessment of Persons with Disabilities in the NWT - Summary Report**. The presentation of information is in keeping with the manner in which it was collected. To maintain confidentiality, information has not been presented where small numbers of people participated or the potential exists for individuals to be identified.

1.2 Objectives and Parameters

The purpose of the Needs Assessment of Persons with Disabilities in the NWT is to provide information for planning appropriate programs and services for persons affected by disability. The Assessment was designed to determine: (Appendix A: Terms of Reference)

- the number and percentage of the NWT population with intellectual, sensory and/or physical disabilities; the nature and distribution of these disabilities; day to day living needs by main type of disability; and issues faced by persons with these disabilities and the issues faced by their families.
- existing programs/services available to persons affected by intellectual, sensory and/or physical disabilities, and the current and projected (5-10 year) service needs of this population.

Early in the research design phase, the Needs Assessment partners broadened the scope of the research to include cognitive (including Alzheimers and late stage alcoholism) and learning disabilities. The broader scope was an effort to recognize an aging NWT population and a perceived high rate of learning disability among persons of school age. It was decided that a separate assessment would examine the extent of psychiatric disabilities and the program/service needs of this population. Psychiatric disabilities were included in cases where this disability accompanied one or more of the other disabilities under investigation. Each disability was defined to ensure consistency of data and enable comparisons with other research. Both diagnosed and undiagnosed disabilities acknowledged by persons with disability or his/her caregiver were included.

The partners determined that the Needs Assessment would include NWT residents of all ages; collect key demographic data; identify the current place of residence of persons with disabilities; and focus on the characteristics/ manifestations of disability rather than diagnostic names or labels. The Assessment would not have any individual identifiers or include persons with disabilities living outside the NWT.

1.3 Needs Assessment Methodology

The Needs Assessment began in January 1999 and was completed in June 2000. As shown in the chronology in Appendix B, the Assessment was undertaken in three phases:

1. Planning and Design (January 1999-August 1999)
2. Field Work (August 1999-March 2000)
3. Data Compilation and Reporting (December 1999-June 2000)

During the three phases, the Disabilities Needs Assessment Project Working Group had 16 meetings. These meetings together with other intergroup

communication, enabled the partners and Lutra's research team to collaborate on:

- defining each of the five types of disability under investigation.
- the design, testing (in Yellowknife and Rae-Edzo) and revamping of questionnaires.
- promoting and encouraging participation in the Needs Assessment.
- responses to various concerns, for example limited capacity of front-line workers to participate and inadequate resources for the Assessment.

Good communications among the partners was essential to managing the many challenges associated with building an unique partnership within the context of a difficult and sensitive research study.

Consistent with the basic premise of social programs in the NWT, a collaborative approach was adopted for the Needs Assessment. The approach and methodology for the Assessment were influenced by five factors:

1. a target population largely unknown to the general public;
2. a lack of baseline or similar studies on disabilities in the NWT;
3. the interests and mandates of the partners;
4. a short time frame;[2] and
5. limited resources.

Collaboration among, and active participation of front-line workers were central to effectively dealing with these factors. To this end, the Assessment relied heavily on front-line human service workers in NWT communities to identify, engage and assist persons affected by disability to participate. It was assumed that:

1. front-line workers would most likely be aware of persons affected by disability; able to differentiate activities associated with disability from

[2]Initially, a three-month time frame was envisioned for the Needs Assessment.

those related to poor socio-economic circumstances; facilitate disclosure of disability; and provide ongoing support to persons affected by disability.

2. front-line collaboration would improve community participation in the research, increase ownership and recognition of disability issues, and maximize resource efficiencies.

Multiple research instruments were developed for the Needs Assessment. (Appendix C) Each had a distinct target:

1. a **preliminary scoping interview guide** to focus discussions with program managers about regional programs/services for, and clients affected by disability. Lutra's research team conducted 44 interviews with program managers in Inuvik, Norman Wells, Fort Simpson, Hay River, Fort Smith and Yellowknife.
2. a self-administered **Community Service Provider Questionnaire** to enumerate direct client services, and current and future service uses and needs. This questionnaire was provided to over 300 human service agencies in NWT communities.
3. a self-administered **Personal Questionnaire** to collect information on persons with disability and their perspectives on living with disability. This questionnaire was mainly distributed to persons with disability known to community service providers. Some Personal Questionnaires were mailed directly to persons known to have a disability by the Workers Compensation Board of the NWT, the NWT Income Support Program in Yellowknife and the NWT Council for Disabled Persons.
4. a self-administered **Parent/Caregiver Questionnaire** to collect information on the needs of unpaid caregivers. This questionnaire was mainly distributed to caregivers by community service providers and local researchers.
5. a **focus group discussion guide** to refine and confirm the data collected.

This guide was developed as a companion to community reports on disability in Yellowknife and Fort Smith.

Many front-line workers had difficulty dedicating time and priority to the Assessment due to heavy work loads and vacant positions. In addition, persons affected by disability required considerable assistance to complete the questionnaires. This was mainly due to low literacy levels and discomfort or unfamiliarity with the concept or language of disability. Additional resources brought into the Assessment mid-way through the field work enabled the hiring of skilled and trusted local researchers to work with front-line community service providers. Researchers assisted persons with disability and parents/unpaid caregivers to complete questionnaires. Front-line workers and researchers involved in the Needs Assessment are listed in Appendix D.

Data from the three questionnaires were compiled in ACCESS data bases and data analyses were undertaken using SPSS software. Questionnaires were reviewed and entered on a community by community basis to enable the research team to discern data problems and trends. For example, in communities such as Rae-Edzo and Holman where a language other than English dominates, there was some confusion in the interpretation of cognitive, learning and intellectual disabilities which required verification. In other communities, genetic conditions might contribute to higher rates of sensory or physical disability. The reasons for high rates of a particular type of disability were discussed with community service providers and/or local researchers in some communities.

To assist in data analysis, focus groups were conducted in Yellowknife and Fort Smith. A full day workshop was also held in Yellowknife to review the draft findings report, make recommendations for changes, and plan for follow-up. The workshop was attended by the Needs Assessment partners, representatives from

non-profit organizations, CEOs from regional health and social services boards, and persons interested in disability.

1.4 Participation

In total, the voices of 1259 NWT people affected by disabilities are presented in this Needs Assessment of Persons with Disabilities. (Table 1)

- 44 regional programs managers participated in scoping interviews.
- 807 people with disabilities completed Personal Questionnaires.
- 227 people completed Parent/Caregiver Questionnaires.
- 181 people completed Community Service Provider Questionnaires.

Table 1: Regional/Community Participation in the NWT Needs Assessment, 2000

Region and Community	Questionnaires Completed		
	Personal	Parent/Caregiver	Community Service Provider
Beaufort	**64**	**18**	**18**
-Paulatuk	3	1	5
-Holman	29	9	5
-Sachs	2	-	3
-Tuktoyaktuk	30	8	5
Delta	**112**	**42**	**27**
-Inuvik	38	15	13
-Aklavik	30	9	6
-McPherson	26	15	4
-Tsiigehtchic	18	3	4
Sahtu	**33**	**13**	**30**
-Norman Wells	4	-	7
-Good Hope	10	2	6
-Deline	4	3	7
-Tulita	12	5	6
-Colville	3	3	4

Region and Community	Questionnaires Completed		
	Personal	Parent/Caregiver	Community Service Provider
South Slave	**154**	**28**	**18**
-Hay River	58	7	4
-Enterprise	1	0	0
-Fort Smith	75	4	8
-Resolution	19	10	5
-Lutsel K'e	1	7	1
Dogrib Region	**106**	**32**	**9**
-Rae-Edzo	87	20	7
-Wha Ti	6	6	1
-Rae Lakes	12	6	1
-Snare Lake	1	0	0
Deh Cho	**83**	**27**	**14**
-Simpson	22	5	8
-Providence	31	7	2
-Kakisa	0	0	0
-Wrigley	8	6	0
-Liard	8	3	2
-Trout Lake	7	4	1
-Nahanni	0	0	0
-Jean Marie	2	1	1
-Hay River Reserve	5	1	0
-Yellowknife	**241**	**62**	**64**
-Dettah/Ndilo	**11**	**5**	**1**
Total	**807***	**227**	**181**

*Three questionnaires were received from people living outside the NWT (Hinton, Iqaluit, Edmonton).

The opportunity to describe daily life with disability and express views on disability was greatly appreciated by participants. At the same time, a variety of barriers were identified as limiting participation. These barriers are the main reasons that the Needs Assessment did not achieve a census of persons with disability in the NWT. The questionnaires were intimidating, unappealing or difficult for some respondents. The participation of community service providers

was negatively effected by: staff-turnover, heavy work loads and limited time availability; lack of knowledge about disability and/or poor client information; and a perception that the Assessment was irrelevant to their program/service or client base. Parents/ caregivers and persons with disabilities who declined to participate, may also have felt that the Assessment was too personal or emotional. Others were sceptical about the value of participating in another survey.

Perceived stigmas and lack of awareness or any previous discussion about disability created difficulties engaging persons with disabilities, parents/ caregivers and service providers in this Assessment. Front-line workers and local researchers reported that many individuals are unaccustomed to talking about disability, particularly disabilities which are not visible. In some communities, disability is not recognized or distinguished from social dysfunction while in others, disability is acknowledged but not openly discussed for the shame, fear, anger or despair such discussion may elicit. On an individual level, disability is not a well understood concept. *"I never learned to talk about my disability to anyone. It was good to talk to somebody that understood."* (from Personal Questionnaire) In some situations, individuals passively accept the limitations and difficulties of daily living with disability. Others live with the hope that the condition will go away. *"First time I thought of having a disability. (I was) hoping that (my) back problem can be cured."* (from Personal Questionnaire) Some service providers wished to avoid discussion of disability in order not to create expectations for services for which there are no resources.

The quality and completeness of information collected in this Assessment was greatest among persons with disabilities. Information from the 807 Personal Questionnaires is the basis for this report. These data are supported by information collected in Parent/Caregiver and the Community Service Provider Questionnaires, anecdotal information gathered throughout the Assessment

process and to a limited extent, by information drawn from other research.

1.5 Other Research on Disability in the NWT

In the last two decades, information on disabilities has increased mainly due to the 1986 and 1991 national Health and Activity Limitation Surveys (HALS). HALS is the most complete source of information on disability in the NWT. Less complete information on disabilities in the NWT was collected in the 1991 Aboriginal Peoples' Survey, the 1996 Canada Census, and the 1994 National Population Health Study. The GNWT, Health and Social Services, Aged, Disabled and Chronically Ill studies, NWT Housing Corporation Housing Needs Studies, and the most recent (1999) NWT Labour Force Survey also provide some information on disability. (see Appendix E - Bibliography)

Number of Persons with Disability

The 1991 HALS found that 12.6% of the population in NWT/Nunavut have a disability compared to 15.5% in Canada. This means that in 1999 an estimated 5,453 NWT residents have a disability. The 1996 Census also identified a lower rate of disability in the NWT than in Canada as a whole, 6.3% of the population compared to 10%. (Table 2) A greater proportion of elderly people in the Canadian population than in the NWT, is given as the main reason for lower rates of disability in the north.

Compared to the 1991 HALS, people with mild disabilities are not well identified through the Census. HALS uses a number of detailed questions which result in more persons with mild disabilities being identified.[3] The 1991 HALS found that two-thirds of persons with disability in the NWT have a mild degree of disability. This means that in 1999 an estimated 3,674 NWT residents have a mild degree

---

[3]Housing, Family and Social Statistics Division. no date. **User Guide, Disability Data in the 1996 Census**. Statistics Canada

of disability.

Table 2: The NWT/Nunavut Population with Disability by Percent and Age, 1986, 1991 and 1996

Age Group	Canada					NWT/Nunavut		
	1986		1991		1996	1986	1991	1996*
	Census	HALS	Census	HALS	Census	HALS	HALS	Census
All	9.3	13.2	8.4	15.5	10	8.7	12.6	6.3
0-14 years	2.3	5	2.6	7	3	5.5	7.5	2.8
15-64years	8.2	11	7.2	13	8.5	7.9	13.1	6.4
65+ years	32.4	46	27.5	46	31.4	65.6	59.9	36.1

*The 1996 Canada Census refers to the NWT only. Nunavut is not included.

Notes:

Disabilities included in HALS are mobility, agility, seeing, hearing, speaking and other (psychiatric, intellectual and learning).

The Canada Census considered long term physical and mental conditions, health problems and disabilities.

The 1991 Aboriginal Peoples Survey (APS) investigated disability among NWT/Nunavut adults of Aboriginal ancestry and found that 26.7% (4,695 people) have a disability. More than three-quarters (77%) of Aboriginal adults with disability in NWT/Nunavut have a mild degree of disability. The APS found that disability increases with age. Among Aboriginal adults, the disability rate among persons:

- 15-34 years of age is 19%;
- 35-54 years of age is 31%; and
- 55+ years of age is 57%.

The 1994 National Population Health Survey estimates that 16% of the NWT population 12 or more years of age have a long term physical or mental condition or a health problem limiting activity. (Table 3) This compares to 20% in Canada as a whole. As shown in Table 3, the rate of disability among elderly persons is almost four times that of persons 45-64 years of age. This same survey also

found that NWT people 65 or more years of age are almost twice as likely as Canadians of the same age to report long-term disability or activity limitation.[4]

Table 3: Percent of the NWT Population 12 Years of Age and Older Reporting a Disability by Age, 1994

Self-Reported Long-Term Activity Limitations	PERCENT OF NWT POPULATION				
	12 Years & Older	12 to 24 Years	25 to 44 Years	45 to 64 Years	65+ Years
	16%	13%	13%	19%	74%

Source: 1994 National Population Health Survey and the NWT Health Status Report, 1999 based on the question -"Because of a long-term physical or mental condition or a health problem, are you limited in the kind or amount of activity you can do?"

Note: Data for the 65+ age group should be used with caution given the small number of people interviewed

A study into disability in Nunavut in 1998 drew from the 1991 Aboriginal People's Survey to report that 25.5% of the adult population in the new territory have a disability.[5] The study also collected additional information from 112 Nunavut residents with disability. The small number of people surveyed did not provide any new information on disability in Nunavut.

The Territorial Hospital Insurance Act provides the framework for data collection by those agencies delivering mandated services under the act. Data are coded (known as ICD-9 or 10 codes) in accordance with guidelines. Data collected relate to the presenting problem at the time of a visit/admittance to a health

---

[4]Health and Social Services. 1999. **The NWT Health Status Report**. Government of the NWT

[5]Adele Furrie Consulting Inc. June 1998. **Disability in Nunavut A Demographic Profile**. Nunavut Implementation Commission

facility. Data are not linked to disability or overall health condition of individuals.[6]

Other information has been collected on disability in the NWT through surveys and assessments conducted in specific regions/communities. In 1999, the NWT Labour Force Survey found that 6% of the NWT population 15 or more years of age were unable to work due to age or long-term disability. The majority of persons unable to work for these reasons are 65 or more years of age and 2.5% are 15-64 years of age.

Research on disability among children is limited in Canada and in the NWT. In 1993, GNWT Education, Culture and Employment examined the needs of school age children and found that almost one-third of NWT/Nunavut students have special needs that are not met by the regular school program. An estimated 6% of students had an individualized education plan (IEP) but 13% required this assistance. It is unknown whether the IEP was linked to disability. The research also reported that less than 1% of students were receiving and/or required signing assistance, mobility support or physical therapy. Unpublished information available through District Education Council's in the NWT suggest that more than 40% of students have special needs and learning and speech/language disabilities may be present in more than 10% of the NWT student population.[7] The Learning Disabilities Association of Canada estimates that 10%-15% of Canadians may have a learning disability. The Association admits that this disability is not widely understood either by professionals (including educators) or by those having learning difficulties.

---

[6]The Stanton Regional Hospital Rehabilitation Team has identified a need for better client data. They are optimistic that new technologies will encourage greater consistency in client data collection and allow for the integration of inpatient and outpatient data to provide more complete client information. Currently, in and outpatient data are maintained separately.

[7]Personal communication: Doug Blakey, Sahtu District Education Council

At various times in the 1980s and 1990s, GNWT Health and Social Services (H&SS) conducted aged, disabled and chronically ill assessments to identify the level of care required by these populations. The early assessments did not always include children or "hidden" disabilities such as intellectual, learning or cognitive disability. In 1990, GNWT H&SS identified 296 persons in the NWT with disabilities.

Various other research into disability in the NWT has identified:

- an aging NWT population, an incidence of disability that increases with age, and a need for up to 130 more acute care beds and at least 50 more independent housing units to accommodate NWT seniors by the year 2006. In the same study, service providers suggested that persons who have cognitive disabilities (including those who are not seniors) represent a major challenge for providers of northern housing and social services. People with cognitive disability are expected to place added pressures on the service system in the NWT.[8]

- over 5% of the households in Rae-Edzo are likely directly affected by intellectual disability.[9]

- learning problems and fetal development impacted by alcohol among portions of the school age population in Inuvik.[10]

While information on disabilities has improved, the understanding of disability in the NWT continues to be limited by:

---

[8]Treeline Planning Services Ltd. April 1995. **Seniors Housing and Social Needs Study - A Planning Tool to the Year 2005 The Beginning**. the NWT Seniors' Advisory Committee

[9]Lutra Associates Ltd. June 1995. **Coming Home - Community Research into Intellectual Disabilities in Rae-Edzo**. Yellowknife Association for Community Living

[10]Dr. J.C. Godel for the Inuvik Regional Health and Social Services Board. unpublished.

- different definitions, standards, norm-references and service orientations;
- poor access to and/or inappropriate diagnostic services/tools;
- wrong diagnoses and/or reluctance to discuss, label or name disability;
- reluctance to seek assessment/diagnosis;
- lack of programs/services to help or provide information;
- different expectations and priorities, limiting cooperative efforts, appropriate resource allocations, and clearly defined responsibility; and
- lack of disclosure and trust around disability issues.

Regional scoping discussions conducted to launch this Needs Assessment provided little information on the number and distribution of disability. For example, some Inuvik Region Health and Social Services staff suggested that the oil/gas boom and a high level of substance use in the 1960s and 1970s have contributed to the rate of intellectual and learning disability among young adults, and to cognitive disability among older people in the region. The incidence of these disabilities is unknown. In the Sahtu Region, there is a perceived high level of special needs among school age children. The extent to which these needs can be attributed to disability is unknown. Most people with disabilities requiring services must seek them outside the region thus, it is thought that there are few people with disabilities in the region. In Fort Smith, the local Society for Disabled Persons maintains a confidential list of 60 persons with disability in that community.

Elsewhere in Canada, research into disability has been influenced by public attitudes and policy, and by the activism of persons and organizations affected by disability. To some extent, the research has endeavoured to debunk myths about persons with disabilities.

- *Myth - Persons with disabilities are unemployable. Fact - Persons with disabilities have greater difficulty securing employment.* Studies into

employment challenges faced by persons with disability urge consideration of both the disability and the environment when putting supports in place;[11] educational campaigns about disability, funding for supports such as job coaches;[12] and a wide range of holistic professional and peer counselling services to help persons with disabilities adjust after the onset of a disability.[13]

- *Myth - The risk of abuse increases with disability. Fact - The evidence is inconclusive.* Sexual abuse of children and sexual assault of adults with disabilities are widespread phenomena. Research does not exist to either debunk or affirm this notion.

- *Myth - The full rights of citizenship are not exercised by persons with disabilities. Fact - The full rights of citizenship may not be exercised by any group of people marginalized in society.* Research into disabilities in Rankin Inlet, Nunavut in 1994 found that people may not consider themselves to be disabled but are marginalized by policy makers and by the lack of resources allocated to meet their needs.[14] Low literacy and high risk social behaviours have a particular impact on the participation of persons with disabilities (eg. ability to be informed and make decisions). Achieving the full citizenship of persons with disabilities is the intent of the recent federal/provincial/ territorial vision paper **In Unison: A Canadian Approach to Disability Issues.**

---

[11]Fawcett, Gail. 1996. **Living with Disability in Canada: An Economic Portrait**. Office for Disability Issues Human Resources Development Canada, Ottawa.

[12]Persons with Disabilities Project. October 1998. **"Potential...Opportunity...Progress..."** Human Resources Development Canada, Yellowknife

[13]Canadian Paraplegic Association. 1997.

[14]Sappujjijit Friendship Centre. Fall 1994. **Enhancing the Life of Persons with Disabilities**. Rankin Inlet.

- *Myth - Changes in social programs and funding have enhanced the life of persons with disabilities. Fact - Changes in social programs may be causing more people with disability to live independently within their communities but service reductions may be affecting the ability of these people to live safely, securely and with dignity.* Closure of community facilities is impacting persons with psychiatric disabilities, those on income support, and those relying on medical and social supports.[15]

While the knowledge of disabilities has increased in the last two decades, Canadian jurisdictions have been slow to give priority to disability issues. Some have launched initiatives to respond to disability issues. In British Columbia for example, a "disability lens" is being considered to provide policy and program developers with a tool to address the impacts of government programs/services on persons with disabilities. A recent report of the GNWT does not identify disability as a priority issue.[16]

1.6 Validity of the Needs Assessment

In total, 807 persons with disabilities participated in this Needs Assessment. This represents:

- 2% of the estimated 1999 NWT population;
- 15% of the estimated population with disability in the NWT in 1999; and
- 33% of persons with moderate to severe disabilities living in households/ non-institutionalized settings in the NWT in 1999. (Table 4) (Only those

---

[15]SKR (Stan K. Remple) Management Consulting. 1995. A **Proposal for Community Supports to Enhance Independent Living for Persons with Intellectual Disabilities in the Northwest Territories**. for the Yellowknife Association for Community Living

[16]Minister's Forum on Health and Social Services. January 2000. **Our Communities Our Decisions - Let's get on with it! Final Report**. Health and Social Services Government of the NWT

persons incarcerated or living in extended care facilities/hospital wards are considered to be living in institutionalized settings.)

Compared to the whole NWT population with disability (Table 4), the Needs Assessment involved:

- more elderly people,
- a similar portion of children, and
- fewer adults.

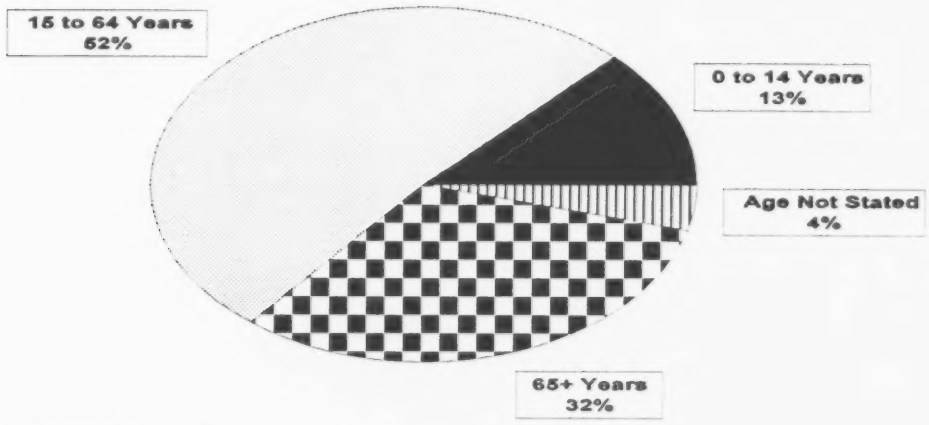
Table 4: Distribution of the NWT Population in 1999 and NWT Needs Assessment Respondents with Disability by Age, 2000

Age Groups	NWT Population	NWT Population with Disability[1]	Needs Assessment Respondents with Disability
Total	41,606	5,453	807
0-14 years	27.2%	15.7%	12.7%
15-64 years	68.7%	67.8%	51.5%
65+ years	4.1%	16.5%	32.2%
unknown	-	-	3.6%

[1] Estimated based on HAL and GNWT population estimates for 1999

More than one-half of persons with disabilities participating in the Needs Assessment are between 15 and 64 years of age and 13% are children 0 to 14 years of age. (Figure 1)

Figure 1: Persons with Disability by Age, NWT Needs Assessment 2000



N (Number of Respondents) =807

This Needs Assessment involved more persons with moderate to severe than mild disability.(Table 5) Persons with moderate to severe disability are more likely than those with mild disability to:

- accept or acknowledge disability and therefore have participated in the Assessment.
- have an assessment/diagnosis or a disability named by a professional.
- have multiple disabilities.
- be known or to use services in the community.

As shown in Table 5, persons with mild/slight disability make-up the majority (67%) of persons with disability in the NWT. The tendency toward mild disability was also found among Aboriginal adults in NWT/Nunavut reporting disability in the 1991 Aboriginal Peoples Survey. This Assessment involved only 2% of NWT

residents who reported mild disabilities in HALS.[17]

Table 5: Severity of Disability by Percent of the NWT Population Reporting Disability in 1999 and in the 2000 NWT Needs Assessment (as a Percent of the NWT Population with Disability)

	Estimated 1999 NWT Population with Disability Living in Households n = 5,453[1]		2000 Needs Assessment Percent of Persons with Disabilities[2] n = 807	
Mild/Slight	67%	(n=3,674)	2%	(n=85)
Moderate	23%	(n=1,259)	17%	(n=209)
Severe	10%	(n=521)	73%	(n=379)
Moderate/Severe	33%	(n=1780)	33%	(n=588)

[1] Based on rates derived from 1991 HALS and 1999 NWT population projections.
[2] 2000 Needs Assessment data are presented as a percent of the estimated 1999 population with disability by severity based on 1991 HALS rates.

In this Needs Assessment, the representation of persons with moderate to severe disability living in households (rather than institutions) is a valid base for projecting to the whole NWT population with moderate to severe disability living in households. (A detailed discussion generalizing the results of the Needs Assessment to the total population with disabilities in the NWT is provided in Appendix F.) Should the needs of NWT persons with mild disability change for example, due to employment or lifestyle circumstances, the needs presented in this Assessment would be severely under-represented. For instance, changes in family or economic circumstances for some persons with intellectual disability could reduce the structure and routine available to support daily living activities. For some persons with intellectual disability, these changes could cause an otherwise mild disability to be seen as a moderate or severe disability.

[17]The 1991 Health and Activity Limitation Survey was used as a benchmark to estimate the total number persons with disability and the severity of disability in the NWT.

1.7 Projections of the NWT Population with Disability

It is estimated that the total number of persons with disability living in households will grow from 5,453 in 1999 to 7,883 in 2019.[18] (Table 6) Appendix F provides a discussion of the methodology used to calculate projected changes in the NWT population with disability.

Table 6: Projected Number of Persons Living in Households in the NWT with Disability by Severity, 1999-2019

	1999	2004	2009	2014	2019
Mild	3674	3928	4239	4616	4964
Moderate	1259	1379	1548	1740	1903
Severe	521	603	728	885	1016
Total	**5453**	**5910**	**6515**	**7241**	**7883**

1.8 Research Notes

The Needs Assessment of Persons with Disabilities has the following limitations.

- **Comparability of Data**

The 1991 Health and Activity Limitation Survey (HALS) provides the most complete data on disability in the NWT. While definitions developed for this Needs Assessment endeavoured to enable comparability of data, HALS does not:

- define physical disability (but rather the imitations associated with mobility and agility),
- disaggregate data on cognitive, intellectual, learning or

[18]Projections are derived from the 1991 HALS and population projections for the NWT.

psychiatric disabilities, or
- collect detailed information on children or the ethnicity of persons with various types of disability.

These factors limit comparability of data.

- **Cognitive, Intellectual and Learning Disability**

Cognitive, intellectual and learning disabilities are not widely understood, accepted or acknowledged. Persons of all backgrounds had difficulty understanding the subtle differences for example, between intellectual and learning disability (eg. rate of learning verses the way of learning). These challenges were particularly great among Aboriginal language users. Other persons may not have recorded these "hidden" disabilities in their Personal Questionnaire or may not have participate in the Needs Assessment at all.

- **Participation of Children**

The information on disability among children is sparse in the 1991 HALS, the 1991 Aboriginal Peoples Survey and the 1996 Canada Census. Unfortunately, this Needs Assessment provides little additional information on this segment of the population. Slightly more than 100 children with disability participated in this Needs Assessment. This small number limits the extent to which definitive statements can be made about NWT children with disability. Concurrent to this research, NWT schools were assessing student needs including those of students with disabilities. Linking information from the two assessments will be important to understanding the needs of NWT children with disability.

- **Psychiatric Disability**

Data presented on psychiatric disability refer only to those persons who also have one or more of the other disabilities under investigation. No definition of psychiatric disability was provided. Data on psychiatric disability should be treated as a very limited perspective on the needs of persons with this disability.

- **Needs of Persons with Mild Disability**

Persons with a mild degree of disability did not participate in this Assessment and may not be known by community service providers. As such, the needs of persons with mild disability are not well understood through this Assessment.

- **Under-Representation of Service Needs**

This Needs Assessment sought information on a broad range of programs and services which may be available in the NWT. A variety of programs/services may exist in some communities but not in others. In other cases, services/programs may be available but delivered to the individual in a location outside of the NWT. Lack of understanding, experience or exposure to a full range of programs and services may limit the extent to which individuals (especially those in smaller communities) can assess their program/service needs now and in the future. Data on service use and needs provided by community service providers were incomplete, limiting their usefulness in corroborating information provided by persons affected by disability.

2. People with Disabilities in the NWT

This chapter contains a demographic profile of persons with disability in the NWT. It also offers a description of the types and severity of disability within the NWT population. Unless otherwise specified, descriptions of persons with disabilities refer to persons with moderate to severe disability living in households in the NWT.

2.1 An Introduction to People with Disability

Gender

Both the 1991 Health and Activity Limitation Survey (HALS) and the 1996 Census found that a slightly higher proportion of NWT persons with disability are males, 52% compared to 48% female.[19] An equal percentage of males and females with disability participated in this Needs Assessment.

Gender may be a factor in some types of disability. Physical disability is frequently associated with industrial work and work place health-related conditions. Physical disability tends to be more prevalent among Canadian males than females. This Needs Assessment found that more NWT females than males have physical disability. Illness/disease are the main reason for physical disability in the NWT. (see Figure 13, pg. 45) Males in the NWT are more likely than females to have speech, learning and intellectual disabilities. (Figure 2 pg.25) Speech, learning and intellectual disabilities among males may be linked to foetus size or more frequent difficulties at birth.[20]

This Needs Assessment also found that males (57%) are more likely to have

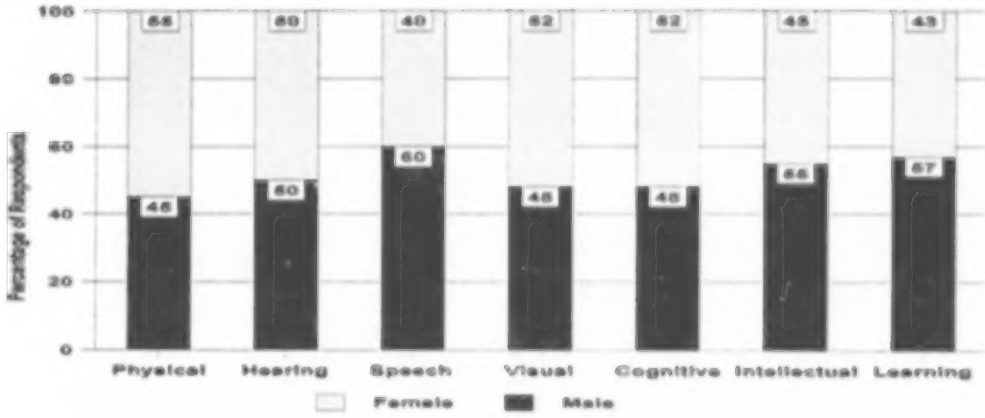
---

[19]NWT HALS data include Nunavut. 1996 Canada Census data are reported for the NWT only.

[20]from statements made at the April 2000 Disabilities Needs Assessment partners and stakeholders workshop.

unpaid caregivers/parents than females (44%).

Figure 2: Gender of Persons by Type of Disability and Percent, NWT Needs Assessment 2000



Ethnicity and Language

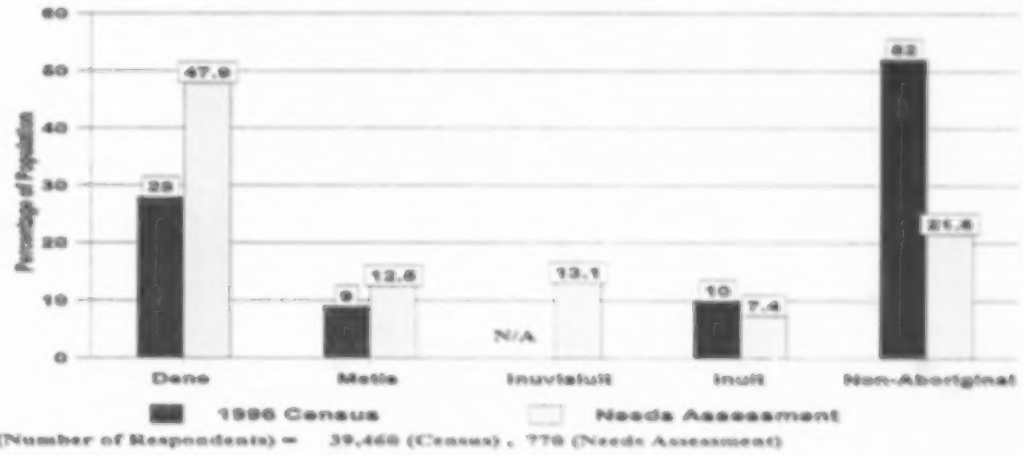
The GNWT's 1999 population estimates for the NWT show slightly more Aboriginal people (51%) than persons of non-Aboriginal ancestry. In 1996, non-Aboriginal people made-up 52% of the population. The disability rate within the Aboriginal adult population in the NWT is about 27%, more than twice the rate for the NWT population as a whole.[21]

Almost eight of every ten people with a disability participating in this Needs Assessment have Aboriginal ancestry. Compared to other Aboriginal people, the incidence of disability is greatest among the Dene. (Figure 3) Higher rates of disability among Aboriginal people may partly account for over-representation of this population in the Assessment. Good participation of persons with disability in

[21] 1991 Aboriginal Peoples Survey and 1991 HALS

predominantly Aboriginal communities (where they are known by front-line workers) also contributes to the larger number of Aboriginal persons with disability in this Assessment.

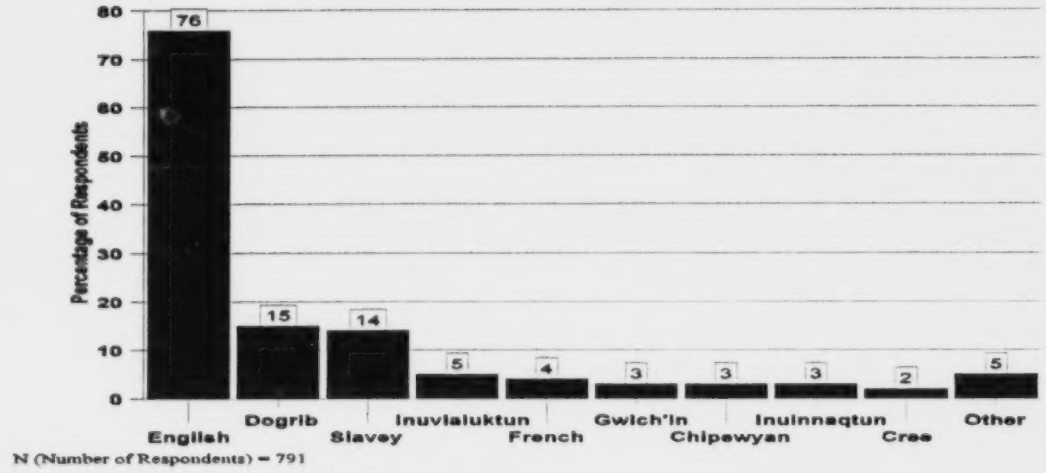
Figure 3: Ethnicity of Persons with Disability, NWT Needs Assessment 2000 Compared to the 1996 Census



Note: This Assessment did not involve individuals living outside the NWT

The NWT has eight official languages. Six of these are Aboriginal languages. The 1996 Canada Census identified English as the home language of 92% of NWT residents. Home language is synonymous with the language best understood. Over-three quarters (76%) of persons with disabilities participating in this Needs Assessment say they understand English best. (Figure 4) The remaining one-quarter understand a variety of other NWT official languages and other languages of the world (eg. German and Italian) best. Persons with disability who understand a language better than English are most likely to identify Dogrib or Slavey.

Figure 4: Language Understood Best by Percent of Persons with Disability, NWT Needs Assessment 2000



Note:
Percentages do not sum to 100 due to multiple responses. "Other" includes Inuktitut, American Sign Language and other languages.

Residency and Care

People with disability in the NWT are not a mobile population. Compared to all other communities in the NWT, persons with disability living in Yellowknife and Hay River are most likely to have been born outside the NWT. (Table 7) Regardless of ancestry or place of birth, almost all persons with disability (96%) consider their home to be in the same community or region in which they now live. This also holds true for the City of Yellowknife, where 94% of persons with disability consider this community or the Yellowknife region to be their home. This might suggest that persons coming from other communities to Yellowknife for services, easily accept the City as their home. It might also speak to the notion or sense of community among persons with disability.

Table 7: Number of Persons Born and Residing in NWT Regions by Current Residence and Ethnicity, NWT Needs Assessment 2000

	Residing in Yellowknife		Residing in Hay River/Hay River Reserve		Residing in Inuvik		Residing in Fort Smith	
N=	104	112	42	16	27	3	57	13
Born in	Abor	Non-Abor	Abor	Non-Abor	Abor	Non-Abor	Abor	Non-Abor
Yellowknife	23	12	0	0	0	0	1	1
North Slave	13	0	0	0	0	0	0	0
South Slave	9	1	20	2	0	0	36	2
Deh Cho	9	0	13	0	0	0	0	0
Sahtu	5	0	1	0	1	0	0	0
Beaufort/Delta	17	1	0	1	20	1	2	0
Outside NWT	27	98	8	13	3	2	18	10
Bush	1	0	0	0	3	0	0	0

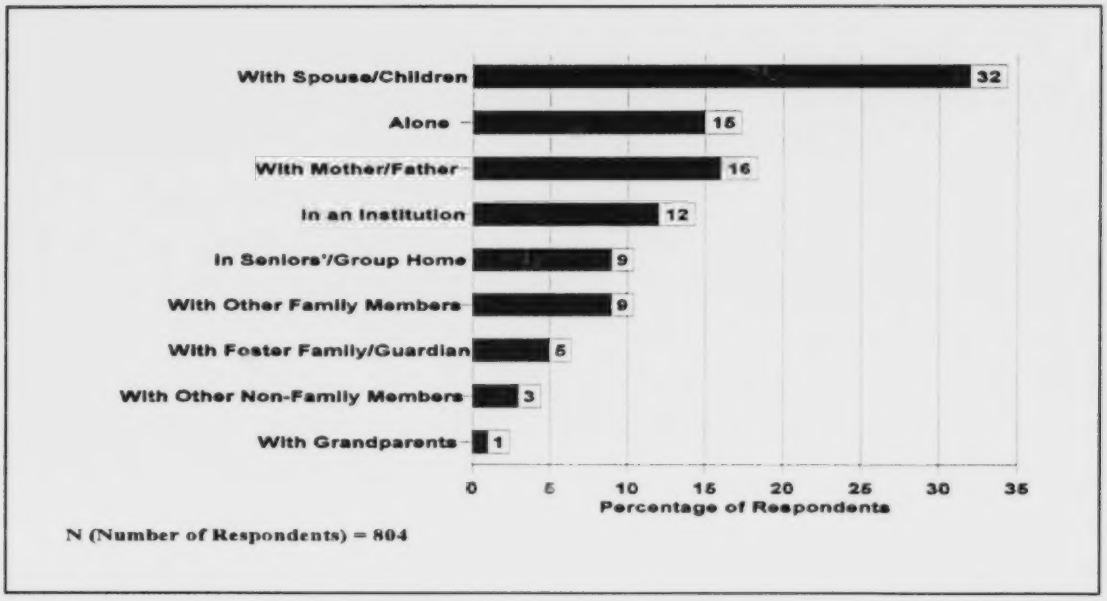
Note:
"Abor" = person of Aboriginal ancestry "Non-Abor" = person of non-Aboriginal ancestry

The HALS does not provide detailed information on persons with disability living in institutions or persons younger than 15 years of age. For the rest of the population, HALS reports that 69% of adults with disability residing in households in Canada and 83% in the NWT/Nunavut, live in a (Census) family household.[22] Among persons with disability participating in this Needs Assessment, most live in a family environment. (Figure 5) Compared to all other age groups, persons with disability 65 or more years of age are least likely to live in a family environment. The availability of housing and/or care options and/or a reluctance

[22]A Census household is defined as a now married couple or a couple living common-law with or without never-married children of either or both spouses, or a lone parent of any marital status with at least one never-married son or daughter living in the same dwelling.

to move away from family or community may be the main influences on the living circumstances of persons with disability in the NWT.

Figure 5: Place of Residence of Persons with Disability, NWT Needs Assessment 2000



Note: This Assessment did not involve individuals living outside of the NWT.

Marital Status and Dependents

Both the 1991 HALS and this Needs Assessment found that NWT persons with disability 15 years of age and older, are unlikely to be in a marital relationship. This Needs Assessment found that over two-thirds (67%) of persons of adults 15 years and older were single, divorced, separated or widowed. More than half of adults with disability (56%) have no one depending on them for food/shelter/ clothing but almost one-quarter (22%) have three or more dependents. (Table 8) An equal number of male and female adults with disability have dependents.

Table 8: Family Circumstances of Persons with Disability 15 or More Years of Age by Percent, NWT Needs Assessment 2000

Marital Status	
-Married/Common-Law (n=207)	32%
-Single (n=246)	40%
-Divorced/Separated/Widowed (n=174)	27%
Dependents (eg. for food/shelter/clothing) (n=605)	
-None	56%
-1 or 2	22%
-More than 3	22%

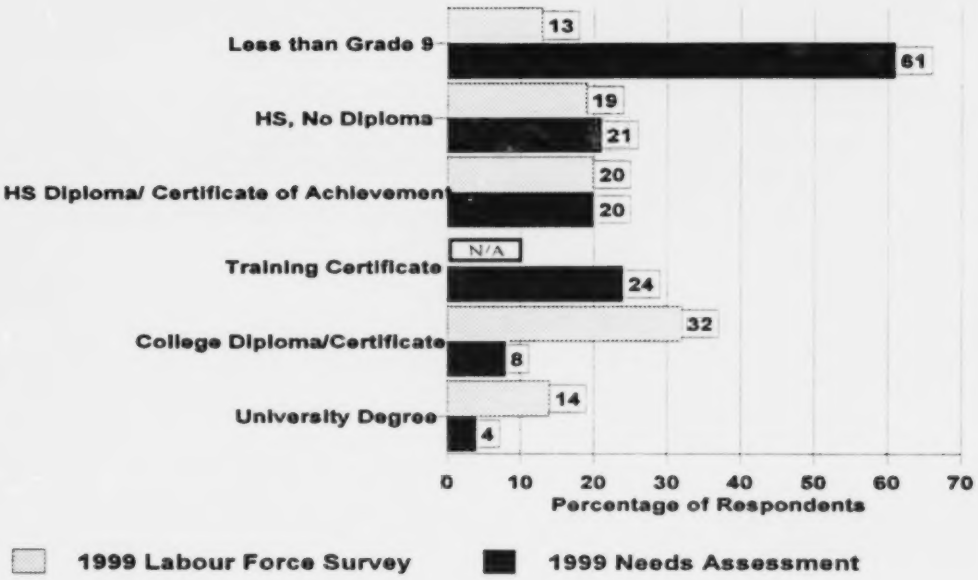
Education, Employment and Income

In the NWT, less than grade 9 education is defined as functional illiteracy. Rates of illiteracy are linked to opportunities to access and achieve successes in education. The 1999 NWT Labour Force Survey found that 13% of the whole NWT population and 26% of the Aboriginal population 15 years of age and older have less than grade 9 education. HALS reported that 40% of NWT/Nunavut adults with disability 15 to 64 years of age have less than grade 9. More than half of the adults (61%) with disability participating in this Needs Assessment have this level of education. (Figure 6) The high rate of illiteracy among persons with disability may be linked to the lack of representation by persons with mild disability, and high proportion of persons with Aboriginal ancestry and elderly persons in this Needs Assessment.

Education levels vary by age among persons with disability. (Table 9) Among persons with disability 15 years of age and older participating in this Assessment,

- the highest levels of education are among persons 40-59 years of age.
- more than half (58%) of persons 25-39 years and 60+ years (57%) have not achieved grade 9.

Figure 6: Formal Education of Adults with Disability, NWT Needs Assessment 2000 Compared to the 1999 NWT Labour Force Survey



Note:

1. Percentages do not total 100% due to multiple responses (eg. less than grade 9 and a training certificate).
2. Both this Needs Assessment and the GNWT's 1999 NWT Labour Force Survey consider adults as persons 15+ years of age.

The 1999 NWT Labour Force Survey reported a strong correlation between education and employment rates.[23] This Needs Assessment corroborates this finding. The employment rate for persons with disability with grade 12 or more education participating in this Assessment is ten times the rate for persons with less than grade 9 education. (Figure 7)

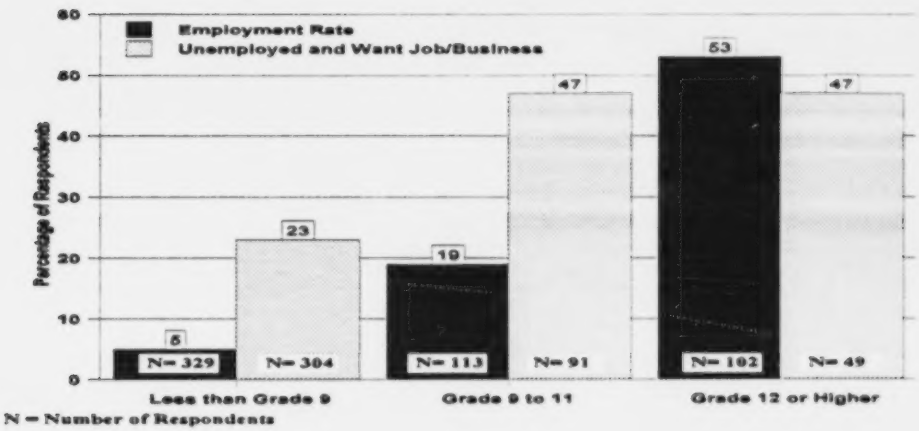
---

[23]The employment rate is the percent of persons 15 or more years of age who were employed at the time of the Labour Force Survey.

Table 9: Education of Persons with Disability by Age, NWT Needs Assessment 2000

	15-24 years	25-39 years	40-59 years	60+ years
Less than Grade 9	36%	58%	39%	57%
High School/No Diploma	38%	15%	25%	9%
High School Diploma/Certificate of Achievement	21%	14%	21%	11%
Training Certificate	14%	14%	30%	13%
College Diploma/Certificate	-	5%	12%	5%
University Degree	-	4%	11%	5%
n=	58	111	197	309

Figure 7: Employment Activity of Adults by Level of education, NWT Needs Assessment 2000



Note: The employment rate is based on the percentage of persons with a job or running a business.

In 1999, the employment rate in the NWT for persons 15 to 59 years of age was 71% and 53% for persons of Aboriginal ancestry.[24] The employment rate is 26% among people with disability in this age group. Just over one-half (51%) of adults with disability 15 to 59 years of age would like to work but can't due to disability or illness. Overall, 16% of persons 15 or more years of age with disability participating in this Needs Assessment are employed/running a business.

Average personal income in the NWT is $33,712. (Bureau of Statistics) In other regions of Canada, poverty is defined as having income of less than $20,000 per year. The NWT does not have an established "poverty line". Among adults with disability participating in this Needs Assessment, 80% have personal incomes of less than $20,000/year and 48% have personal incomes of less than $10,000/year. A large percentage of adults with disability (44%) live in households with less than $20,000 in total household income. (Figure 8) Low levels of income create significant challenges for persons participating in this Needs Assessment. Throughout this Needs Assessment, the lack of sufficient financial resources was identified as the most pressing issue faced in daily living with disability.

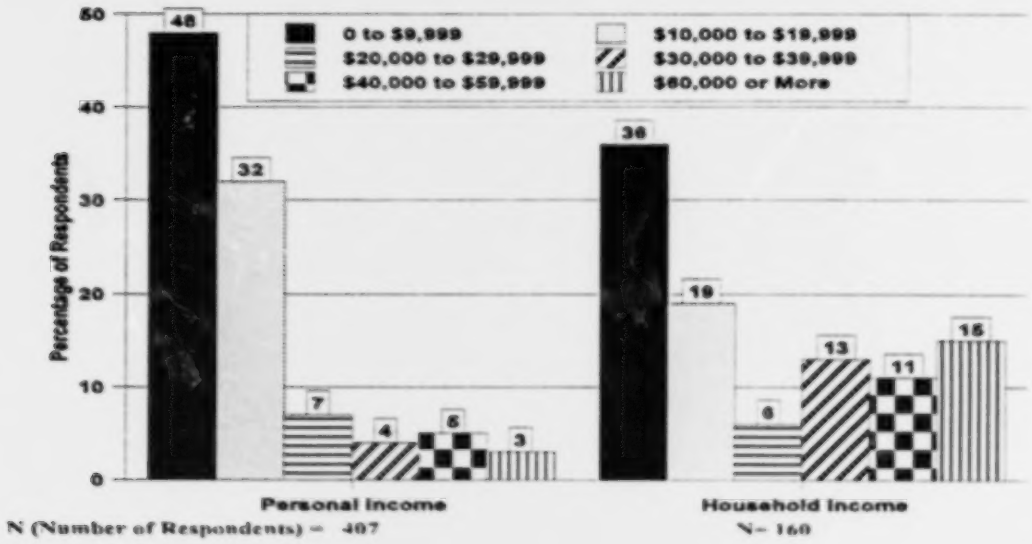
"*I don't know what my personal income is or how that is defined in a subsistence lifestyle.*" (from Personal Questionnaire)

Approximately one-half (52%) of adults participating in this Needs Assessment are currently receiving income support, need it now but are not receiving it, or may need it in the future. Over half (56%) of adults currently receiving income support live with other people and 27% live alone.

---

[24] 1999 NWT Labour Force Survey

Figure 8: Personal and Household Income Levels by Percent of Respondents, NWT Needs Assessment 2000

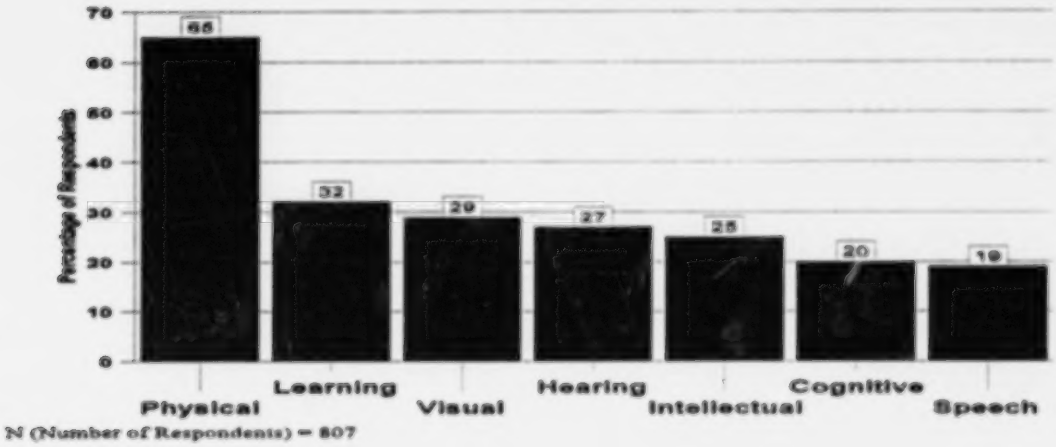


2.2 Describing Disability

Type of Disability

Among persons with moderate to severe disability living in NWT households, 88% have a physical or sensory disability. Learning disabilities affect almost one-third of persons with disability. (Figure 9) Approximately 60% are living with more than one disability. Almost 10% also have a psychiatric disability.

Figure 9: Type of Disability by Percent, NWT Needs Assessment 2000



Compared to the HALS and Aboriginal Peoples' Survey,[25] fewer Needs Assessment respondents have hearing disability and more have speech disabilities. (Table 10) The high rate of hearing disability in Nunavut may account for these differences.[26] Higher rates of speech disability may be associated with the difficulties developing language skills and in learning, recorded in this Assessment. Higher rates of visual disability in the NWT may be due in part, to the:

- excellent participation in this Assessment of the Canadian National Institute for the Blind (CNIB), and/or
- extent of known genetic conditions impacting on vision in some communities around Great Slave Lake and the efforts by service providers to include these persons in this Assessment.

---

[25]Both surveys do not separate NWT and Nunavut data.

[26]1991 Aboriginal Peoples Survey and the 1998 Nunavut Needs Assessment

Table 10: 1991, 1994 and 2000 Percent of the NWT Population with Disability by Type

	NWT/Nunavut (Aboriginal Peoples' Survey 1991)	NWT/Nunavut (HALS 1991)	NWT (1994 National Population Health Survey)	Needs Assessment 2000*
Physical -Mobility -Agility	- 33.5 25.3	- 35% 30%	- 36.4% -	65% - -
Hearing	41%	47%	41.5%	27%
Speech	7%	7%	29.3%	19%
Visual	22%	10%	20.8%	29%
Mental -Cognitive -Intellectual -Learning	32.4	32% (including psychiatric, intellectual & learning)	-	- 20% 25% 32%

Notes:

*Refers to percentage of persons participating in this Assessment.

Almost 10% of persons with one or more of the five disabilities under investigation in the Needs Assessment also identified a psychiatric disability.

The Learning Disabilities Association of Canada estimates that 10%-15% of the Canadian population may be affected by learning disability.

- Almost one-third of persons with disabilities participating in this Needs Assessment identified a learning disability.
- One-fifth of persons participating in this Assessment identified a cognitive disability.
- One-quarter identified an intellectual disability.

Community service providers and program managers suggest that the rates of brain-related disability may be conservative. These professionals explain this point of view by the sustained levels of high risk behaviours including substance abuse, in many NWT communities for at least three decades.

Table 11 compares the distribution of disability in the NWT by age reported in the 1991 HALS and in this Needs Assessment.

Table 11: The Nature of Disability by Age, 1991 Health and Activity Limitation Survey for NWT/Nunavut and the NWT Needs Assessment, 2000

	0-14 years		15-64 years		65+ years		Total	
	1991	2000	1991	2000	1991	2000	1991	2000
Type of Disability	1425	103	4785	414	855	261	7065	807***
Physical		30		265		204		521
Mobility	--	--	1875	--	585	--	2460	
Agility	--	--	1645	--	495	--	2140	
Seeing	140	13	405	107	200	94	745	230
Hearing	430	11	1765	87	375	108	3315	217
Speaking	225	51	290	76	--	23	515	153
Other	110*	--	1520	--	250	--	1880	
Cognitive	--	20		62		67		159
Intellectual	--	58		116		17		198
Learning	--	72		140		37		255
Mental Health Condition**	135							
Nature Not Specified	---	---	355		--		370	

Source: 1991 Health and Activity Limitation Survey - Total Population is for Persons 15+.
Notes: HALS data do not include persons in institutions.
Other includes: intellectual disability, mental health condition, or learning disability.
*children 0-14, the classification is Other Condition or Health Problem and includes a long-term condition or health problem which is not included in the above categories
**Mental Health Condition in the case of HALS includes long-term emotional, psychological, nervous or mental condition. In the case of the Needs Assessment, refers to psychiatric disability
***Includes 29 individuals who did not state their age.

As shown in Table 11:

- HALS reported that 30% of NWT children (0 to 14 years of age) with disability have a hearing disability and about 16% have difficulty speaking. Among this age group, this Needs Assessment found that:
  - 70% have learning disability;
  - 56% have intellectual disability; and
  - 50% have speech disability.
- HALS found that mobility, hearing and agility limitations are encountered by

34%-39% of working age adults (15-64 years) in the NWT/Nunavut with disability. Among this group age, this Needs Assessment found that:

- 64% have physical disability;
- 34% have learning disability;
- 28% have intellectual disability; and
- 26% have visual disability.

- HALS found that among persons 65 years of age or more with disability, mobility, agility and hearing difficulties were the main difficulties faced. This Needs Assessment found that:
  - 78% have physical disability;
  - 41% have hearing disability
  - 36% have visual disability; and

Severity and Assessment of Disability

The vast majority (92%) of persons with disability participating in this Assessment reported an assessed/diagnosed/named (by a professional) disability. The reasons for the high level of known disability may be due to:

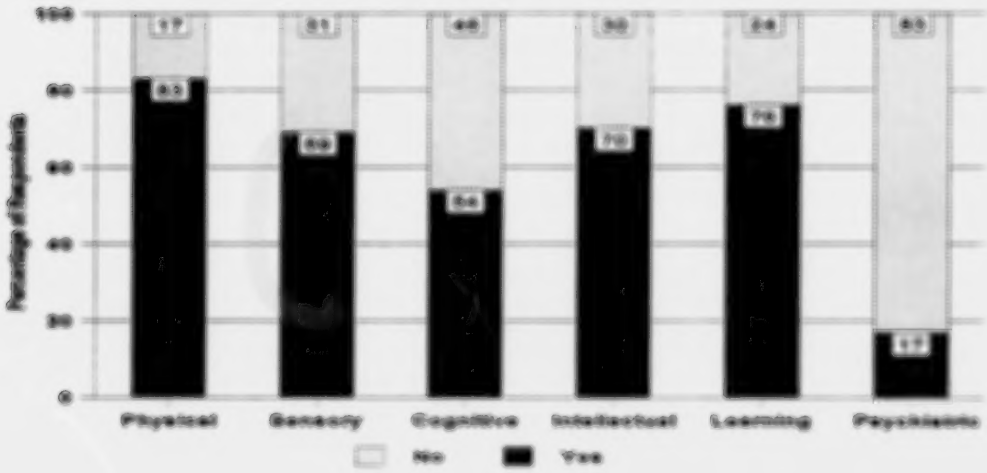
- the methodology employed for this Needs Assessment, namely the requirement for persons to acknowledge and accept their disability;

- the involvement of community service providers in identifying and inviting participants (eg. those with known disabilities and those using services); and

- the inclusion of naming by a professional as an option to assessment or diagnosis.

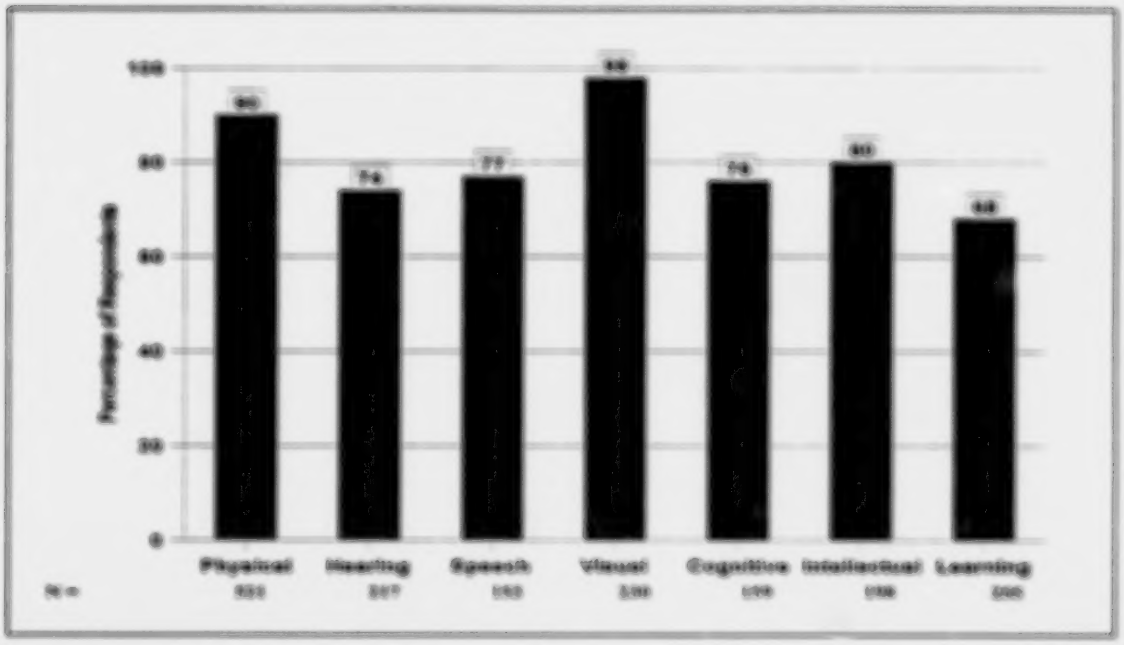
Parents/caregivers of persons with disability confirm the high level of assessment/diagnosis/naming among the persons they care for. (Figure 10)

Figure 10: Diagnosed and Assessed Disability (including those named by a professional) by Percent of Parents/Caregivers Caring for Persons with Disabilities, NWT Needs Assessment 2000



As shown in Figure 11, persons with visual disability are most likely and persons with learning disability are least likely to have an assessed/diagnosed/named disability. A lower level of assessment/diagnosis/naming of learning disability may be due to limited assessment/diagnostic services in the NWT combined with less understanding or recognition of this disability. Difficulties associated with understanding/naming learning disability were exemplified in this Assessment by the caregivers/parents of children/youth attending education programs endorsed by the Learning Disabilities Association in Yellowknife. Most declined to assist their children/youth to complete a Personal Questionnaire.

Figure 11: Percent of Persons Having an Assessed/Diagnosed/Named Disability, NWT Needs Assessment 2000



Note:
Among those people identifying a psychiatric disability in addition to one or more of the disabilities under investigation, 82% stated that the psychiatric disability had been assessed/diagnosed or named by a professional.

This Needs Assessment showed a high level of assessment/diagnosis/naming of intellectual disability (80%). This may be due to the tendency of persons to have moderate to severe intellectual disability, the inclusion of naming by a professional as an option to assessment/diagnosis or to recent efforts to bring

attention to the impact of alcohol and drug use on fetal development.[27]

The detailed questions included in the 1991 HALS tended to identify persons with mild, moderate and severe disabilities while the 1996 Census tended not to include persons with mild disabilities. In 1991, HALS reported that 33% of persons with disabilities in the NWT/Nunavut had moderate or severe disabilities and 67% had mild disabilities. The majority (77%) of Aboriginal adults enumerated in the 1991 Aboriginal Peoples Survey also identified a mild disability. As shown in Table 5 (page 20), only 2% of persons reporting mild disability in the HALS are represented in this Assessment.

Among persons with disability participating in this Needs Assessment, 60% have multiple disabilities. Most persons participating in this Needs Assessment tended to assess their disability (or at least one of their disabilities) as moderate to severe. (Table 12) Only 12% of Needs Assessment respondents described their disability (or all disabilities) as mild.

Parents/caregivers of persons with disability also tended to assess the disability of the person cared for as moderate to severe. Only 12% of parent/caregivers described the person in their care as having a mild disability. The remaining parents/caregivers described the disability of the person cared for as moderate (32%) or severe (56%).

---

[27]For example the Yellowknife Association for Community Living's video and handbook "Helping Families Helping Children" to assist families raising children affected by Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Effects (FAE).

Table 12: A Self-Assessment of Disability by Persons with Disabilities, NWT Needs Assessment, 2000

% of Persons with Disability		Mild	Moderate	Severe
Physical	(n=511)	14%	30%	57%
Hearing	(n=207)	24%	34%	42%
Speech	(n=150)	24%	31%	44%
Visual	(n=226)	25%	29%	46%
Cognitive	(n=155)	23%	31%	46%
Intellectual	(n=190)	20%	32%	48%
Learning	(n=248)	16%	38%	46%

Note:
Percentages due not total 100% due to multiple disabilities of differing degrees of severity.

Despite greater participation of persons with mild disability in HALS and greater participation of persons with moderate to severe disability in this Needs Assessment, HALS data draws a stronger relationship between age and severity of disability than this Needs Assessment. (Table 13) This might suggest that while the prevalence of disability in the NWT is influenced by age, the severity is not.

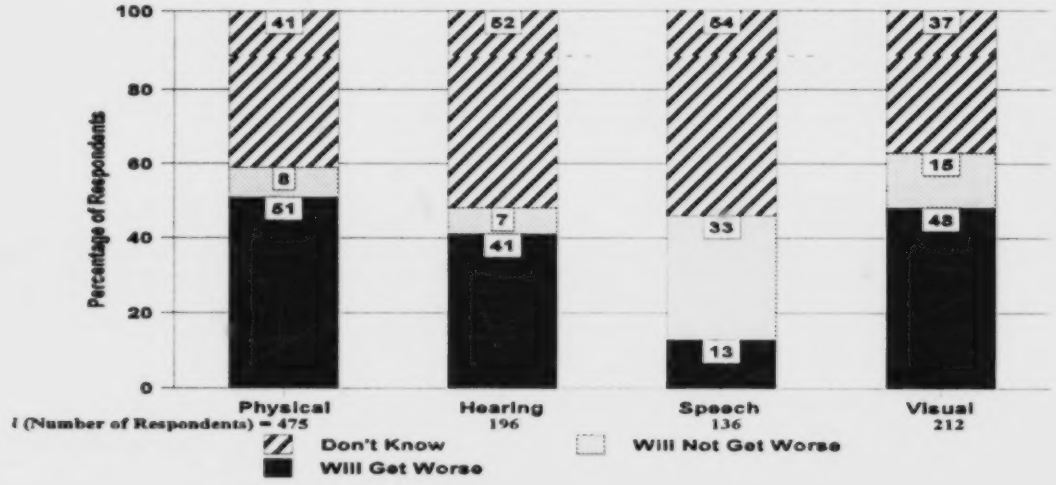
Table 13: Severity of Disability by Age of Persons with Disabilities, NWT Needs Assessment 2000 Compared to the Estimated NWT Population with Disability in 1999

	Needs Assessment 2000			1999 NWT Population with Disability[1]		
	Mild/ Slight	Moderate	Severe	Mild/ Slight	Moderate	Severe
0-14 years	14%	28%	58%	89%	8%	3%
15-64 years	11%	31%	58%	68%	26%	6%
65+ years	12%	29%	59%	42%	28%	30%

[1] Rates derived from the 1991 HALS and the estimated NWT population in 1999.

Approximately 85% of persons with physical, hearing, speech and/or visual disability expect their disability to worsen (50%) or are uncertain about the future condition of their disability. (Figure 12) Compared to persons with physical and/or visual disability, persons with speech and/or hearing disability express the greatest uncertainty about the future of their condition. Uncertainty may be associated with a lack of information or understanding of these disabilities.

Figure 12: Self-Assessment of the Future Condition of Disability by Percent, NWT Needs Assessment 2000



Note: These data were not collected for other disabilities under investigation. The definition of cognitive disability described the condition as usually degenerative. Intellectual and learning disabilities are static conditions usually present at birth.

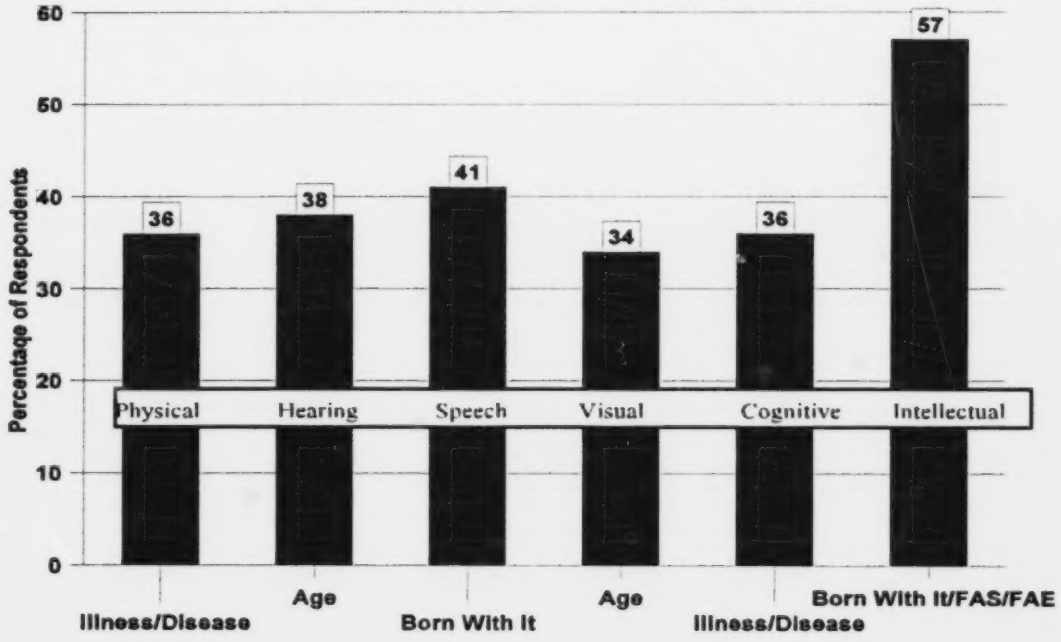
Among persons with disabilities participating in this Needs Assessment, illness, disease or age are the main reasons for physical, hearing, visual and cognitive disability. (Table 14 and Figure 13) Other reasons account for the presence of

speech, intellectual and learning disability. Intellectual disability and learning disability are seen as conditions present at birth. The largest proportion of persons with speech disabilities also say that this condition was present at birth.

Table 14: The Reported Reasons for Disability by Percent of Persons with Disability, NWT Needs Assessment 2000

Reasons	Physical n=518	Hearing n=210	Speech n=150	Visual n=227	Cognitive n=154	Intellectual n=198	Learning n=247
Born with it	15%	11%	41%	20%	3%	47%	34%
Work Injury	11%	9%	1%	4%	2%	1%	1%
Neglected/ Violence/Abuse	1%	3%	4%	3%	6%	4%	6%
Age	22%	38%	7%	34%	32%	4%	10%
Illness/Disease	36%	18%	25%	21%	36%	19%	20%
Accident	13%	7%	2%	10%	4%	5%	3%
Genetic	7%	1%	2%	5%	4%	3%	6%
Don't Know	7%	17%	11%	11%	7%	11%	16%
Pre-Natal Exposure to Alcohol/Drugs	2%	-	4%	-	3%	10%	6%
Own Use of Alcohol/Drugs	4%	2%	5%	3%	14%	6%	9%
Other	2%	2%	4%	6%	2%	3%	4%

Figure 13: The Main Reported Reason for Disability by Percent of Persons with Disability, NWT Needs Assessment 2000



3. LIVING WITH DISABILITY

Actions taken to care for ourselves and participate with others are typically understood as the usual activities of daily living. What special aids, equipment and supports are needed to cope with daily living activities? How does the use of special aids, equipment and supports help people to cope with disability? How do the challenges of daily living activities vary with the type and severity of disability? What work, school and social activities do persons with disabilities participate in? What are the major challenges of living with disability? What are the circumstances and issues faced by parents/caregivers of persons with disability? These are the questions answered in this chapter.

3.1 Use of and Need for Special Aids, Equipment and Support

A variety of special aids, equipment and supports are used by persons with disability to cope with daily living activities. Special aids, equipment and supports can assist persons with disability to overcome limitations in daily living activities, live independently and live with dignity. The use and need for special aids, equipment or supports may be affected by:

- understanding of the disability,
- living and lifestyle activities and circumstances,
- awareness of/access to aids or supports, and
- attitudes about disability.

The extent to which these factors influence the use or need for aids and support can vary with age, and type and severity of disability.

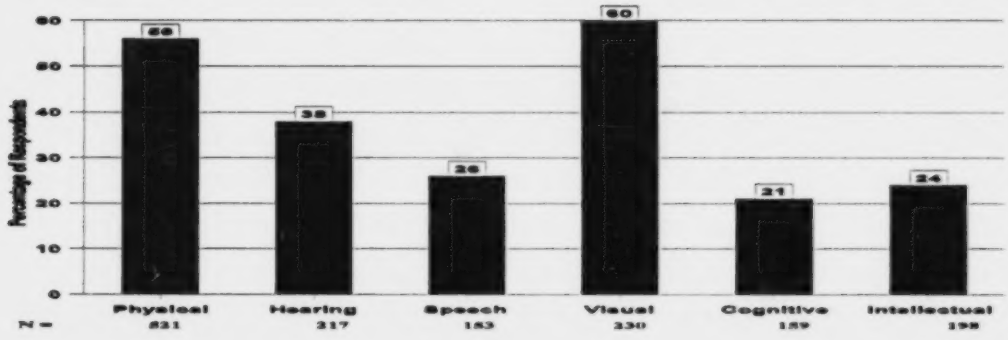
The use of special aids, equipment and support among persons with disability participating in this Needs Assessment should be understood within the context of their main living circumstances. The greatest number of persons with moderate to severe disability living in NWT households:

- are adults or elderly people.
- have a disability assessed/diagnosed/named by a professional.
- live in a family environment but are unlikely to be in a marital relationship.
- are considered illiterate (eg. have less than grade 9 education).
- are not employed or running a business.
- have personal and household incomes of less than $20,000 per year.

In light of these circumstances, this Assessment found that 57% of persons with moderate to severe disability use special aids/equipment/support now. Comparatively, the majority of NWT/Nunavut Aboriginal adults with disability enumerated in the 1991 Aboriginal Peoples Survey, had mild disability. In that same survey, less than one-quarter (24%) reported using specialized aids, equipment or systems and only 3% identified the need for special aids/ equipment/services to be able to work.

This Assessment found that persons with physical and visual disability are more likely to use special aids/equipment/supports than persons with other types of disability. Persons with cognitive disability are least likely to use them. (Figure 14) Persons with learning disabilities were not asked about their use of aids/supports.

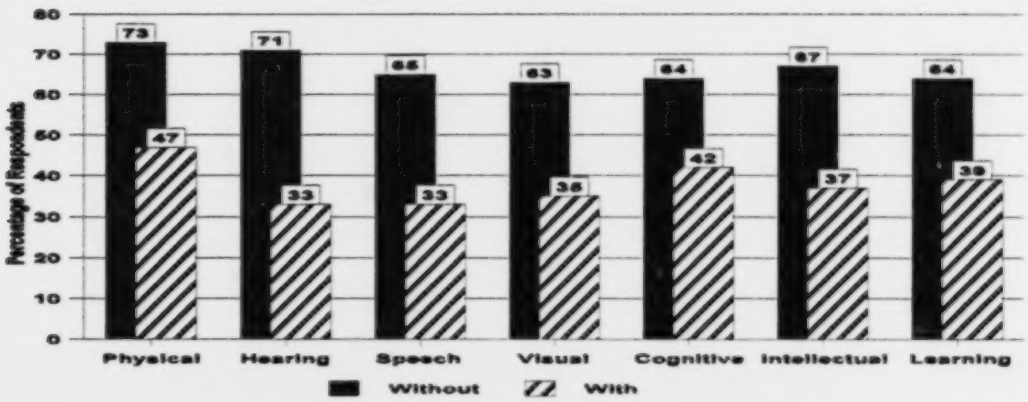
Figure 14: Use of Special Aids/Equipment/Support To Help Cope With Disability by Percent of Respondents, NWT Needs Assessment 2000



Note: Persons with learning disabilities were not asked about their use of special aids/equipment/support.

With the use of special equipment/aids/supports, persons with all types of disability have significantly fewer difficulties in the activities of daily living. (Figure 15)

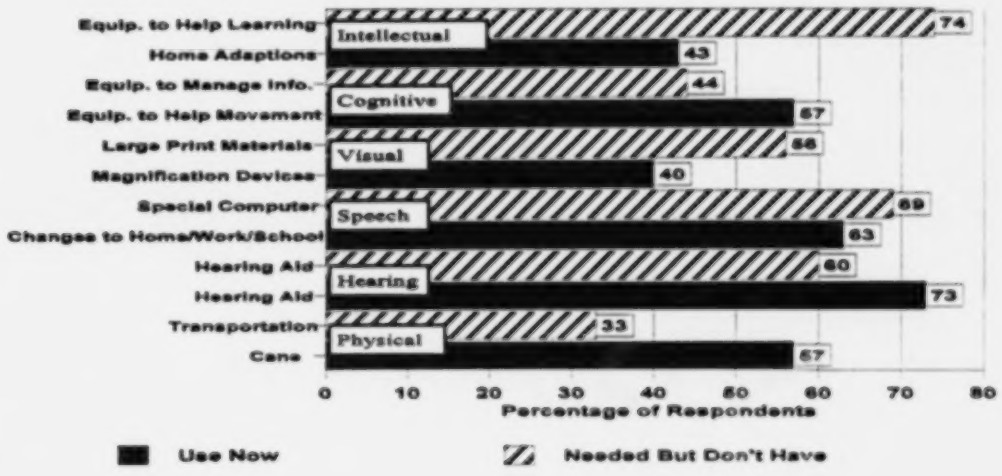
Figure 15: Reported Difficulties Encountered With and Without the Use of Special Equipment/Aids/Supports by Frequency, NWT Needs Assessment 2000



As shown in Figure 16, the need now for special aids/equipment/support (because persons with disabilities do not have them), is great among persons with disability in the NWT. Need may be driven by the absence of aids/ equipment/supports or by the suitability or functionality of them. This was made clear by the significant number of persons with disability who use a special aid/support but also need the same aid/support. For example, some people currently using a hearing aid also identified a need for a hearing aid now. Some people using home care support also identified a need for this support.

Persons with intellectual and speech disabilities have the greatest need for aids/supports. Among persons with speech disability, there is a significant need for special computer equipment and software. The need for equipment to help learning is greatest among persons with intellectual disability. (Figure 16)

Figure 16: Main Special Aids/Equipment/Support Used and Needed by Type of Disability, NWT Needs Assessment 2000



Note: Special aids/equipment/supports for learning disabilities were not investigated.

The 1991 Aboriginal Peoples Survey asked Aboriginal adults with disability in the NWT/Nunavut to identify daily living tasks for which help was needed (eg. preparing meals, shopping for groceries, doing everyday housework, personal care, personal finances, moving about within one's residence, doing heavy household chores). Most Aboriginal adults with disability needing help with these tasks were getting the help they needed.

3.2 Living with Various Types of Disability

Both with and without special aids/supports, persons with moderate to severe disability in the NWT face a variety of difficulties in daily living activities. Daily living challenges vary with the type of disability.

Physical Disability

Lifting, carrying, moving, standing and walking pose the greatest difficulties for persons with physical disabilities. (Table 15) Fewer people with physical disabilities have difficulties associated with working/participating in school or getting/keeping a job. Few people of working age (15-64 years) with physical disability participating in this Assessment are engaged in these daily living activities.

Table 15: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Physical Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With n=244	Without n=379
Feeding, dressing, caring for self	97	155
Lifting, carrying, moving things	144	260
Standing for long periods	157	247
Walking	150	249
Getting in/out of bed	93	149
Bending down	117	184
Reaching, grasping or handling things	96	170
Picking things up	102	185
Working or participating in school	53	91
Getting or keeping a job	54	103
Participating in social/recreational activities	89	147
Playing sports	81	150

Note: A small number of persons with physical disabilities using special equipment/aids/supports also reported difficulty writing and doing housework. Those without special equipment/aids/supports also reported difficulty sewing, bathing, sitting and using stairs.

Persons with physical disability participating in this Assessment use an extensive range of special aids/equipment/supports. Among persons with physical disability:

- over one-half use a cane;
- more than one-quarter use a wheel chair;

- one-fifth use special transportation; and
- one-fifth have adaptations in the home. (Table 16).

Smaller numbers of persons with physical disability use other aids/equipment/ supports.

Table 16: Number of Persons with Physical Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Type of Special Aids/Equipment/ Support	Use Now (n=341)	Need Now (n=179)
Back brace	53	27
Prosthesis	13	6
Cane	194	29
Scooter	4	18
Wheel chair	95	24
Voice activated controls	4	8
Positioning devices	26	23
Special transportation	69	61
Adaptions to motor vehicles	11	32
Adaptions to home	69	70
Adaptions to work	21	35
Adaptions to community buildings	23	36
Special computer equipment	15	20
Long term care	11	11
Oxygen	8	0
Hand/wrist/arm/shoulder brace	8	1
Custom made shoes	5	2

Note: One or two people mentioned other supports such as PT/OT, support groups, various magnets/grabbers, and medications.

Persons with physical disability need adaptations to the home, work/school and community environments as well as special transportation. Persons with physical disability see their ability to participate in their communities being severely limited. They are unable to use fitness facilities, attend the theatre, find suitable housing, access some medical facilities or public services, or use public transportation. "*Doctors send us to physical fitness facilities that are not wheelchair accessible..... medical clinics such as (name of clinic) do not regularly or often enough, clean sidewalks of ice and snow. ...the clinic also does not move*

chairs aside to make (the) foyer wheelchair accessible....(name of another medical clinic) is inaccessible to persons with wheelchairs completely and dangerous to those with other limitations." (from Personal Questionnaire)

Hearing Disability

Even with the use of aids/supports, active and passive communication are the greatest challenges for persons with hearing disability. (Table 17) This Assessment found that only 9% of persons with hearing disabilities use sign language and 15% are able to speech or lip read. Hearing disability has significantly less impact on other facets of daily living, for example playing sports or getting/keeping a job. The reasons for this are likely related to the higher rate of hearing disability among elderly persons, who are less likely to be playing sports or to be in the workforce.

Table 17: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Hearing Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With (n=71)	Without (n=155)
Communicating with others	42	100
Hearing what is being said	61	134
Understanding other people	49	110
Maintaining balance or posture	22	44
Hand/eye or physical coordination	16	31
Getting or keeping a job	12	32
Participating at work or school	16	34
Playing sports or keeping physically fit	13	31
Participating in social/recreation activities	25	58

Note: Without aids/supports, a small number of persons with hearing disabilities also identified difficulty in academic learning, attending public meetings, and using public or business facilities such as movie theatres.

The majority of persons with hearing disabilities who use special aids, equipment and/or support, have hearing aids. These aids are also needed by persons with

hearing disability. (Table 18) Volume controlled phones are also used and are needed by about one-third of persons with hearing disability. Relatively few persons with hearing disability use adaptations in the home or in the work/school or community environments but these adaptations are needed.

Table 18: Number of Persons with Hearing Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/ Support	Use Now (n=97)	Need Now (n= 92)
Hearing aid	71	55
Caption decoder	8	15
Amplification/FM system	18	20
Special computer equipment	4	9
Oral/sign trans/interpretation	23	14
Other translation/aids	9	14
Flashing/visual alarms	12	21
Volume control phone	29	33
Home adaptations	7	21
Work/school adaptation	6	16
Community adaptations	2	21
Long term care	6	6

Speech Disability

Compared to persons with physical or other sensory disability, persons with speech disability experience more difficulties in daily living activities both with and without supports. They face particular difficulty in the work/school environments and in participating in social/recreation activities. (Table 19) The reasons for this may be related to the more youthful population who are affected by this disability.

Table 19: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Speech Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With	Without
Making others understand	44	88
Getting or keeping a job	12	34
Participating at work or at school	21	55
Playing sports or keeping physically fit	15	37
Participating in social/recreation activities	29	54

Note: A small number of persons with speech disabilities also experience difficulty visiting within their communities and making/expressing decisions.

Unlike physical and hearing disability, the need for special aids/equipment/ support among people with speech disability is greater than the current use. (Table 20) Among persons with speech disability, there is a significant unmet need for special computer equipment and software to cope with disability. They also need adaptions in the school/work environment.

Table 20: Number of Persons with Speech Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/ Support	Use Now (n=38)	Need Now (n=48)
Communication board	2	18
Special computer equipment/software	4	33
Speech viewer	6	17
Home adaptations	12	14
School/work adaptations	12	19
Community adaptations	0	15
Long term care	5	5
Speech therapy	3	0

Note: One or two people also mentioned tracheotomy tube, sign language, support workers, oxygen concentrator, prompt cards, medication and the special attention/support of caregivers/SNA.

Visual Disability

Even with supports/aids, persons with visual disability identify reading as the main difficulty encountered in daily living activities. (Table 21) Having access to appropriate materials/devices to enlarge or focus print is part of this problem. It is interesting to note that relatively few people with visual disability identify difficulty in the work/school environment. The reasons for this could be that younger persons with visual disability receive support in the school environment and elderly persons with visual disability tend not to participate in school or work environments.

Table 21: Reported Difficulties With Daily Living Activities With and Without the Use of Special Equipment/Aids/Support by Persons with Visual Disabilities, NWT Needs Assessment 2000

Daily Living Activities	With (n=81)	Without (n=144)
Feeding, dressing and/or caring for self	36	58
Moving around	38	81
Reading	52	101
Writing	39	82
Getting and keeping a job	20	36
Understanding things around me	33	62
Participating at work/school	12	25
Playing sports or keeping physically fit	26	39
Participating in social/recreation activities	28	53

Note: A small number of persons identified difficulty with or without aids/support sewing, housecleaning, watching TV and preparing food for family members.

Among persons with visual disabilities, magnification devices are the main aid used but large print materials are the aids needed the most. (Table 22) The need for adaptations, particularly in the home environment, is also substantial among persons with visual disability.

Table 22: Number of Persons with Visual Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

Special Aids/Equipment/Support	Use Now (n=104)	Need (n=86)
Large print materials	27	48
Large computer monitor	10	46
Special computer software	8	25
Magnification devices	42	27
Braille materials	7	11
Braille equipment	3	7
Audio tapes	15	23
Mobility supports	21	17
Home adaptations	9	26
Work/school adaptation	8	11
Community adaptations	2	17
Glasses	23	0
Long term care	5	5

Note: One or two persons with visual disabilities also mentioned using laser surgery, a signature guide, or a TV reader/spectrum and needing larger print on community/business facilitates such as bank machines, more funding in schools to manage these disabilities or the need for a TV reader/spectrum.

Cognitive, Intellectual and Learning Disabilities

Persons with brain-related disabilities (eg. cognitive, intellectual or learning disability) face similar difficulties in daily living activities. (Table 23) Persons with these disabilities have difficulty understanding things around them, managing money and taking care of themselves, to name a few. These difficulties are more similar to those encountered by persons with speech disability than by persons with physical, hearing or visual disability. The difficulties faced by persons with cognitive, intellectual or learning disability are substantially diminished by the use of special aids/supports/equipment.

Table 23: Daily Living Activities Difficult With and Without the Use of Special Equipment/Aids/Support for Persons with Cognitive, Intellectual and Learning Disabilities, NWT Needs Assessment 2000

Daily Living Activities	Cognitive	Intellectual	Learning
Feeding, dressing and/or caring for self/home			
-With special equipment/aids/support	40 n=67	42 n=75	43 n=99
-Without special equipment/aids/support	60 n=102	84 n=132	80 n=163
Managing Money			
-With	-	46	48
-Without	-	88	91
Moving Around			
-With	37	28	32
-Without	47	45	54
Reading and/or Writing			
-With	34	45	58
-Without	58	86	105
Getting or keeping a job			
-With	20	35	33
-Without	33	75	73
Being understood by others around me			
-With	31	46	54
-Without	65	89	101
Understanding things around me			
-With	36	48	53
-Without	73	98	108
Participating at work or school			
-With	17	36	42
-Without	37	85	99
Playing sports or keeping physically fit			
-With	18	35	31
-Without	32	70	68
Participating in social/recreation activities			
-With	28	50	54
-Without	44	88	93

Note: A small number of persons with cognitive disability mentioned difficulties controlling physical strength or emotions, and remembering. A small number of persons with intellectual disability commented on the embarrassment they feel due to poor memory or difficulty getting to know people.

Similar aids/equipment/supports are used and needed by persons with cognitive and those with intellectual disabilities. (This Assessment did not collect information on special aids/equipment or supports used or needed by persons with learning disabilities.) Among persons with cognitive or intellectual disability, the need for special aids/equipment/supports is greater than current use. (Table 24) Barriers to using aids/support may be related to costs that are not covered by health insurance plans or the availability of the service (due to lack of home/community support workers oriented/skilled to provide services).[28]

Table 24: Number of Persons with Cognitive or Intellectual Disability Who Use and Need Special Aids/Equipment/Support, NWT Needs Assessment 2000

	Cognitive		Intellectual	
Special Aids/Equipment/Support	**Use Now (n=46)**	**Need Now (n=43)**	**Use Now (n=56)**	**Need Now (n=74)**
Equipment to help learning	-	-	16	55
Equipment to help movement	26	13	-	-
Equipment to manage/ organize info	3	19	18	47
Special computer equipment	0	17	7	51
Home adaptations	12	16	24	25
Work/school adaptations	9	12	23	36
Community adaptations	5	13	5	25
Long term care	8	6	2	0
Support workers/special needs assistant	-	-	12	2

Note: One or two persons with intellectual disabilities also identified the use of literacy workshops and medication, and the need for peer support.

Currently, persons with cognitive disability use equipment to assist in movement while persons with intellectual disability mainly use adaptations in the home and work/school environment. The need for equipment to help in learning is great

[28] issues raised by Stanton Regional Hospital's Rehabilitation team.

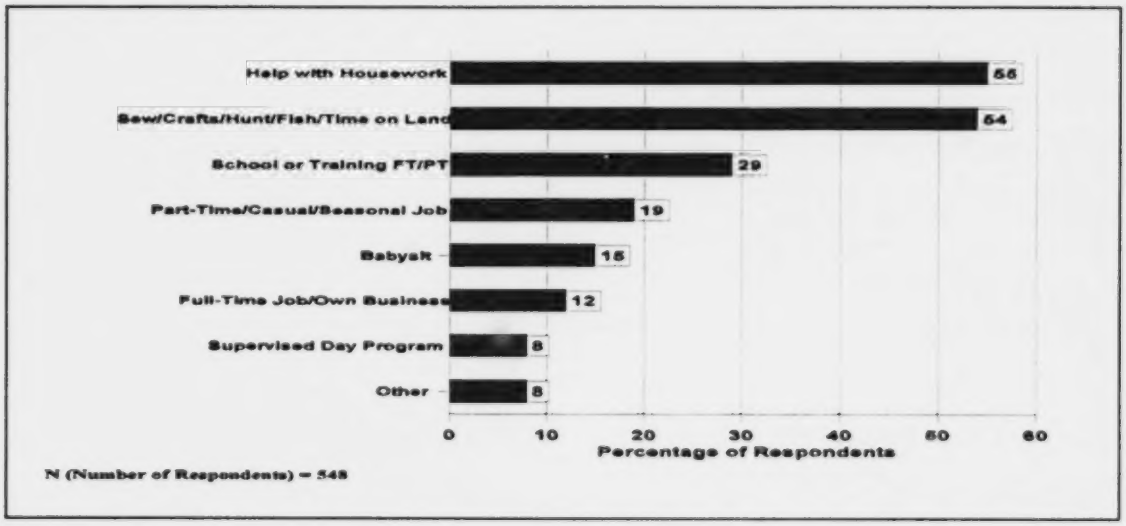
among persons with intellectual disabilities. Among persons with a cognitive or an intellectual disability, the need for equipment to manage/organize information is high.

3.3 Work, Home, School, Recreation and Leisure Activities

Of the 807 persons with disability who participated in this Needs Assessment, 68% described their work, home and/or school activities, and 88% described social recreation and leisure activities. Those who did not provide information may not be engaged in any of these activities.

Figure 17 displays the main daily work, home and/or school activities of persons with disability. Adults and elderly persons with disability participating in this

Figure 17: Daily Activities at Work, Home and/or School by Percent of Persons with Disability, NWT Needs Assessment 2000

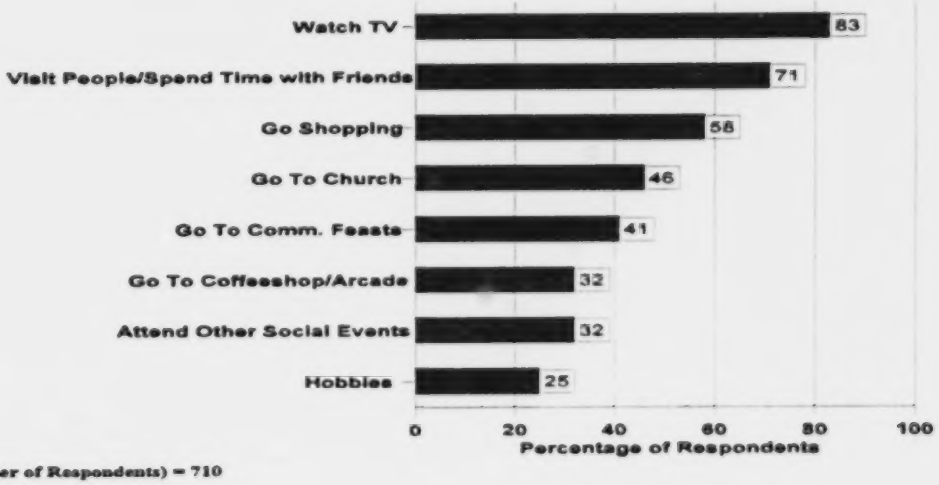


Assessment are engaged mainly in work in the home including sewing or harvesting/land-based activities. Almost all (96%) children of school age

participating in this Assessment go to school full or part-time or attend a supervised program for children.

Recreation, fitness, sports and active living add to life expectancy, physical and mental health and overall well-being and quality of life. Only two-fifths (40%) of adults in the NWT are considered to be active enough for optimal public health benefits.[29] The 1991 HALS reported the main social, recreation and leisure activities of NWT/Nunavut persons with disability as: watching television/listening to radio/music, shopping, and attending social activities including visiting with family and friends. As shown in Figure 18, this Assessment found that watching TV (83%) and visiting or spending time with people (71%) are the main social/ leisure activities of persons with disability in the NWT.

Figure 18: Daily Social, Recreation and Leisure Activities by Percent of Persons with Disability, NWT Needs Assessment 2000



N (Number of Respondents) = 710

[29] from the Canadian Fitness Leisure Research Institute republished by GNWT Municipal and Community Affairs, 2000

This Needs Assessment found that the social, recreation and leisure activities of persons with disabilities do not vary substantially with the size of community and presumably, the variety of social, recreation and leisure options available. Among persons with disabilities living in smaller communities:

- 82% of persons with disabilities watch TV;
- 75% visit people or spend time with friends;
- 59% go shopping;
- 59% go to community feasts;
- 57% go to church; and
- 49% go to community dances.

Among persons with disabilities living in the larger communities of Yellowknife, Hay River, Fort Smith and Inuvik:

- 84% of persons with disabilities watch TV;
- 67% visit people or spend time with friends;
- 57% go shopping;
- 37% go to coffee shop; and
- 35% go to church.

The 1994 National Population Health Survey provides information on the level of physical activity among NWT persons 12 years of age and older. Just over half (51%) of this population were considered inactive; 18% had a moderate level of activity; and 31% were considered active. This Assessment did not ask persons with disability specific questions about their level of physical activity but a small percentage (13%) indicated that they have joined a physical fitness or sports group and 3% said that they exercise.

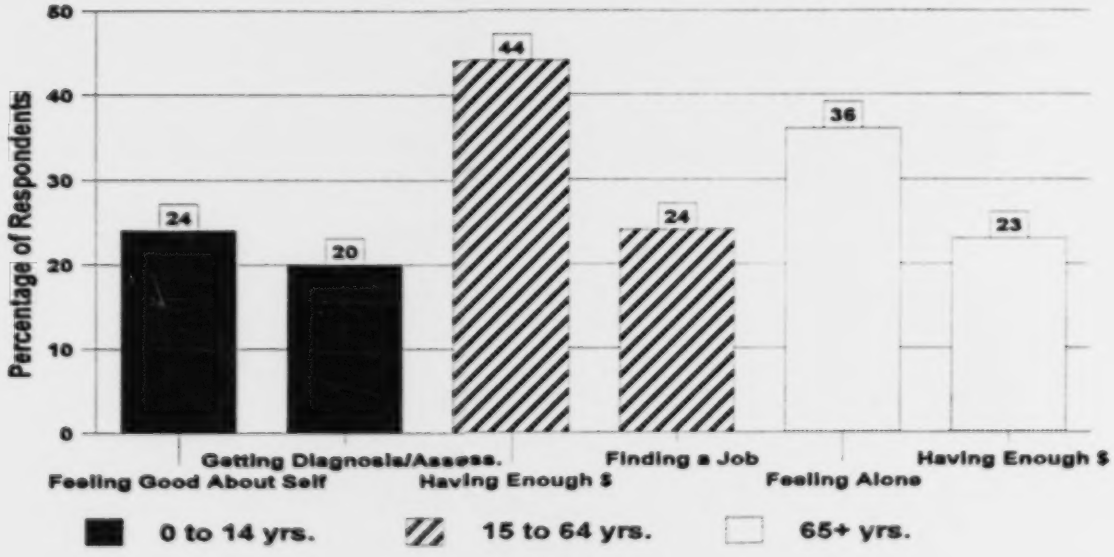
3.4 The Major Challenges of Living with Disability

Persons with disability in the NWT encounter tremendous challenges in daily living. Problems most frequently identified are:

- having enough money (33%).
- feeling alone (23%).
- feeling good about myself (19%).
- getting help from family members (18%).
- getting help with day to day living (17%).

The challenges faced by persons with disability change with age. (Figure 19)

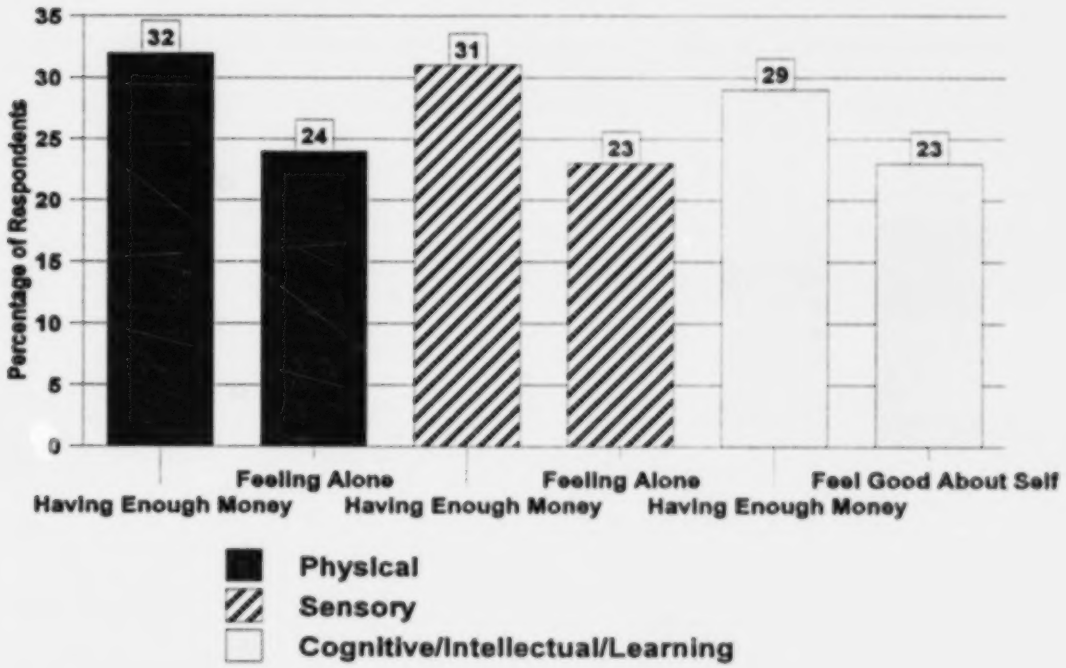
Figure 19: Main Problems Faced in Daily Living by Age and Percent, NWT Needs Assessment 2000



- Children have problems maintaining self-esteem and getting a diagnosis or assessment.
- Adults mainly encounter financial and employment problems.
- Seniors face loneliness and financial issues.

Lack of financial resources is the number one problem facing persons with disability regardless of the type of disability they have. (Figure 20) This is not surprising given that most adults participating in the Needs Assessment have personal and household incomes of less than $20,000/year and live in

Figure 20: Main Problems Faced in Daily Living with Disability by Type and Percent, NWT Needs Assessment 2000



communities with costs of living (exclusive of shelter) that are as much as 110% higher than in Edmonton.[30]

NWT community service providers were asked to identify the problems they believe that persons with disability face. They perceive persons with disability being challenged by:

- the lack of programs and services, (49.3%)
- getting programs/services from qualified people, (31.1%) and
- loneliness and isolation. (25.7%)

Some service providers agree that getting professional diagnosis/assessment (22.2%) and getting support from family members (21.5%) also challenge persons with disability.

This Assessment did not examine in any detail, the extent to which persons with disability have quality of life. Anecdotal information provided by persons with disability suggests that while people participate in activities, the quality of this participation may be less than that enjoyed by other members of society. Loneliness, inadequate financial resources and getting help from people around them are some of the factors impacting on quality of life.

"*Acute hearing loss separates one from most social activities. I go to church but miss the sermon. I go to meetings but come out uninformed. I can carry on a conversation one to one but not in a crowd.*" (from Personal Questionnaire)

"*Disabled people have a culture of their own, which varies somewhat according to the specific disability. Society needs to become more aware of the disability culture and the sub-cultures.... Society must also become more accepting and willing to assist whenever/however it can. Only then will people with disabilities*

---

[30]GNWT Bureau of Statistics

truly feel a part of society." (from Personal Questionnaire)

3.5 Parent/Caregiver Perspectives on Living with Disability

Unpaid caregivers/parents mainly care for children (38%) and working age adults (37%) who are immediate family members. One-quarter (25%) of parents/ caregivers care for persons 65 or more years of age. Persons cared for are more likely to be male than female.

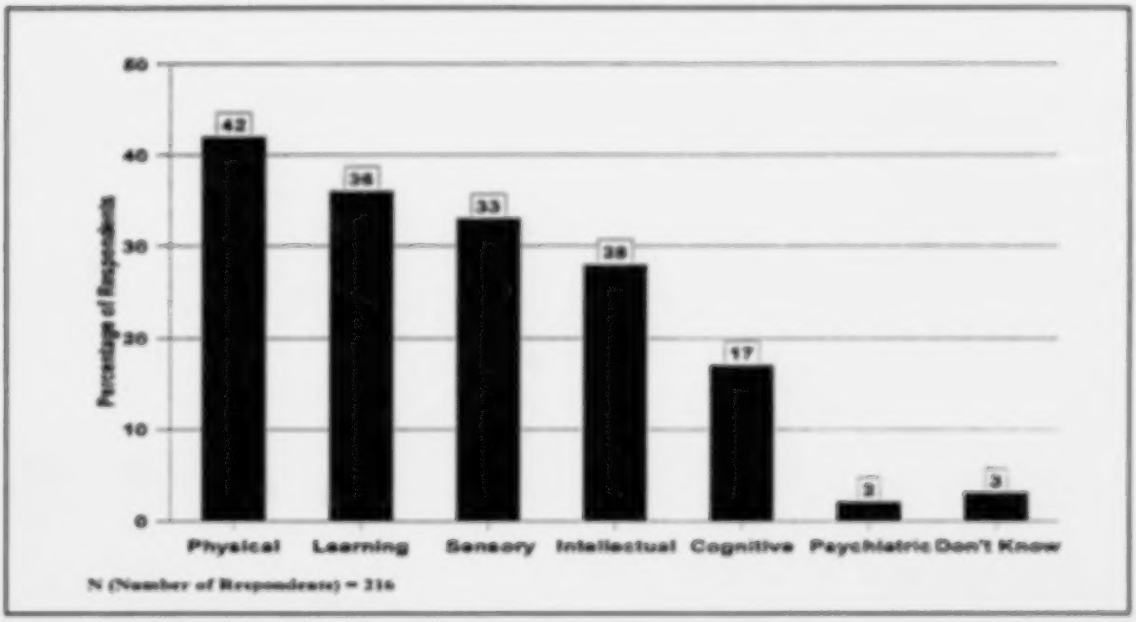
The vast majority (86%) of parents/caregivers say the person with a disability whom they care for, lives with them all of the time. For most (79%) of these caregivers , this means 10 or more hours of care each week. Almost half of parents/caregivers (49.8%) provide constant or 24 hour care and supervision.

Parents/caregivers of persons with disability participating in this Assessment provide care to persons with a range of disabilities. Physical, sensory and learning disabilities are mainly found among persons cared for. (Figure 21) Thirty-seven percent (37%) of parents/unpaid caregivers give care to persons with multiple disabilities.

Parents/caregivers described the behaviours/characteristics of disability of the person cared for. Most frequently, parents/caregivers identify delay developing, difficulty with and/or loss of:

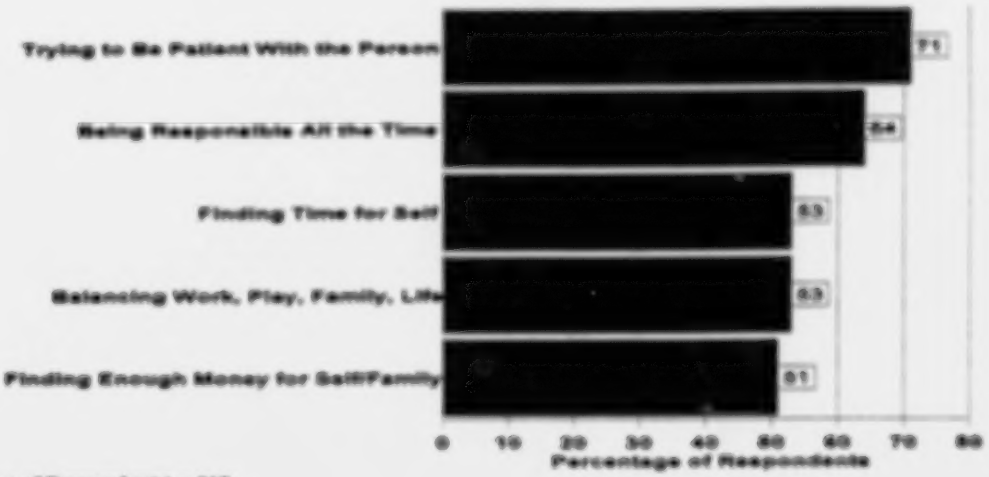
- ability to move quickly or easily/agility or strength or holding/lifting things,
- understanding words/verbal comprehension, remembering, learning new things,
- controlling emotions (eg. anger, fear),
- focussing or paying attention, and
- writing, spelling and reading.

Figure 21: Type of Disability of Person Cared for by Percent of Parents/Caregivers, NWT Needs Assessment 2000



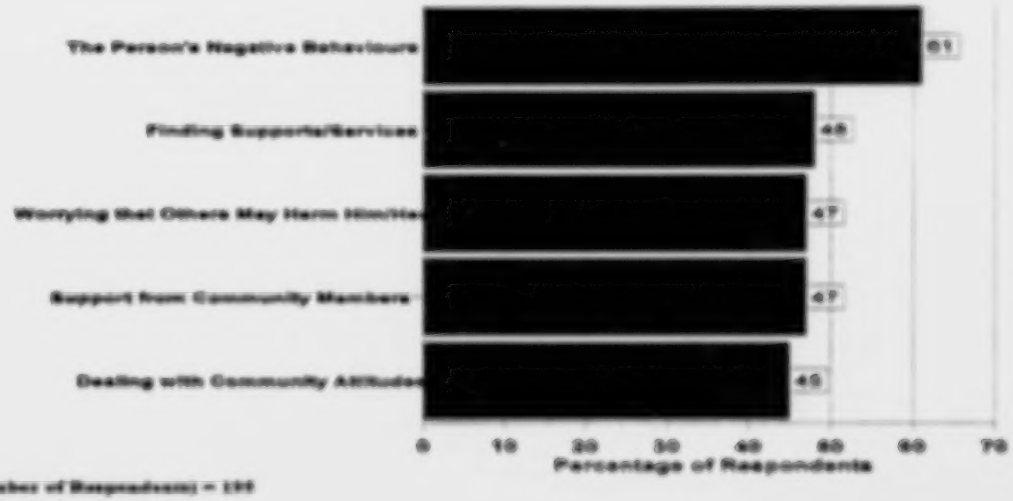
Parents/caregivers of persons with disability face a range of challenges in providing care to persons with disability. (Figures 22 and 23) Personal challenges are significant and seem not to be influenced by the age of the person cared for, the nature or severity of the disability, or the time required to give care. Parents/caregivers of persons with disability require an inordinate amount of patience and sense of responsibility to give care and to manage daily living challenges. Responding to the personal care needs, negative behaviours and poor communications of persons in their care, are difficult for many parents/caregivers. These challenges are exacerbated by difficulties finding professional and community supports/services, and having adequate financial resources. Parents/caregivers also encounter safety and attitudinal issues in their role as caregivers. The challenges confronting NWT parents/caregivers of

Figure 22: Personal Challenges Faced by Parents/Caregivers of Persons with Disabilities, NWT Needs Assessment 2000



N (Number of Respondents) = 317

Figure 23: Other Challenges Faced by Parents/Caregivers of Persons with Disabilities, NWT Needs Assessment 2000

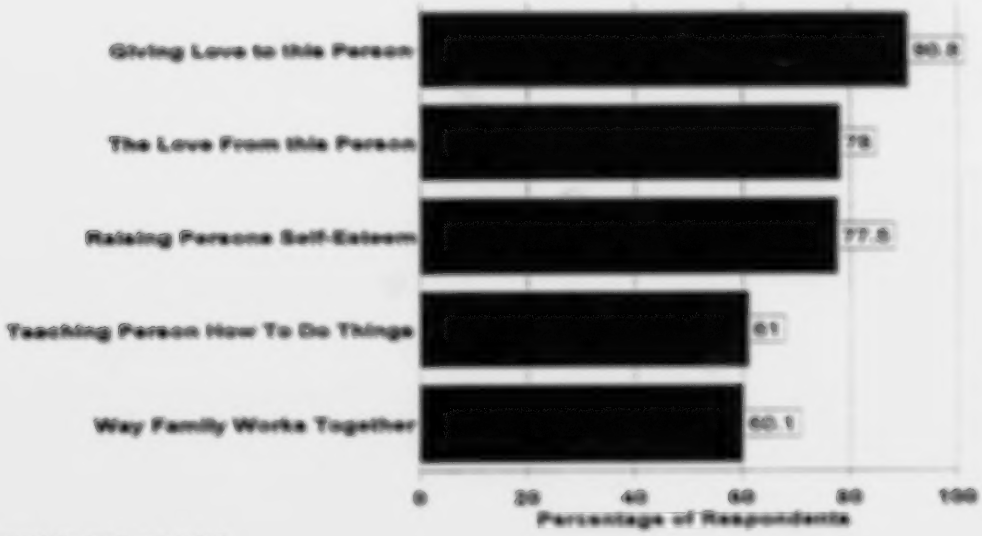


N (Number of Respondents) = 191

persons with disabilities point to the need for respite, training, support services and financial assistance.

Parents/caregivers encounter tremendous challenges in caring for persons with disability but they are clear about the rewards of giving care. Giving love to persons with disability is the greatest reward. (Figure 24)

Figure 24: "Good" Things About Caring for Persons with Disability by Percent of Parents/Caregivers, NWT Needs Assessment 2000



N (Number of Respondents) = 219

4. Programs and Services

What programs/services are used and needed now by persons with disabilities? What programs/services will be needed in the future? What concerns do persons affected by disability have with respect to programs/services? These questions are answered in this chapter. It should be kept in mind that:

- program/service needs refer to those needs of persons with moderate to severe disability.
- familiarity and access to programs and services may result in under-estimates of use and need among persons where programs/services are limited.

In 1999, an estimated 5,543 people living in NWT households had some degree of disability. Of these people, 1780 have a moderate to severe degree of disability and 3,763 have mild disability.

- By the year 2004, there may be 5,910 persons with disability in the NWT of which 1,982 will have moderate to severe disability.

As shown in Appendix F, the population with moderate to severe disability is estimated to be 2,276 in 2009 and 2,919 by the year 2019. Persons with moderate to severe disability are more likely to use and need programs and services than persons with mild disability.

Community service providers participating in this Assessment agree that over the next five years, there will be more people in their communities with some type of disability.

- More than one-third (35%) of community service providers anticipate that the NWT population with disability will increase by 6%-10% over the next five years.
- Another third (34%) expect the population with disability to grow by 1%-5% while 31% forecast increases of 11%-15%.

Most community service providers (81%) identify the high use of alcohol, drugs and solvents as the main factor contributing to a likely increase in the population with disability. Abuse and neglect and an aging population are other factors expected to contribute to a larger population with disabilities. The program/ service needs of an increasing population of persons with disability together with the needs of caregivers will significantly impact on programs/services in the NWT.

"*Our biggest challenges are and will be dealing with cognitively impaired.*" (from Community Service Provider Questionnaire)

"*FAS/FAE are on the rise.*" (from Community Service Provider Questionnaire)

"*FAS impacts the whole community.*"(from Community Service Provider Questionnaire)

4.1 Current and Future Program/Service Needs Among Persons with Disability in the NWT

Generally, programs and services are available to all NWT persons in need, at no cost to the user. Three-quarters (75%) of parents/caregivers of persons with disability say they do not pay for the services they use now. Similarly, community service providers (77%) say that no fee is charged for the programs/services they deliver to persons affected by disability. Among those providers who charge for the program/service, 5% charge the full cost of the service while the remainder levy a nominal or a fee based on income.

Persons with disabilities in the NWT currently use and need a variety of programs and services. In this Needs Assessment, programs/services were segmented

into 10 main types. The Needs Assessment found that:

- the current demand exceeds the availability and/or the capacity of existing programs/services.
- there are nearly as many people who still need services as there are people receiving them now. It is interesting that roughly an equal number of Aboriginal adults with mainly mild disability enumerated in the 1991 Aboriginal Peoples Survey in the NWT/Nunavut needing help in daily living activities were getting the help they needed.
- programs/services in greatest demand are rehabilitation, assessment, specialized/individualized intervention, alternative treatment, financial assistance and advocacy/information.
- programs/services unable to meet the demand today will not be able to cope with expected increases in demand in the future.

The demand for programs/services among persons with moderate to severe disability in the NWT is discussed below and shown in Tables 25 to 34.[31]

Medical/Physical Health Services

Medical/physical health services are available in every community in the NWT. In smaller communities, a basic level of service is available. More complex and a greater variety of services are available in larger centres. Compared to all other types of services, medical/physical health services are the most widely used by persons with disability. General medical care/treatment, testing/diagnosis/ assessment, referral services and home/personal care are the most frequently used services. (Table 25) These and other medical/physical health programs/ services, particularly occupational therapy and physiotherapy, will be needed in

[31]This Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability living in households in the NWT. To provide estimates of the total demand for programs/services by persons with moderate to severe disability living in households in the NWT, the data shown in Tables 25 to 34 are three times that reported by Needs Assessment respondents.

the future.

"(Living with disability is)Feeling pain all the time. Feeling alone with the illness." (from Personal Questionnaire)

Table 25: The NWT Demand for Medical/Physical Health Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/ Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Testing/Diagnosis/Assessment	1026	198	1224	1368	1570
Referral Services	894	177	1071	1189	1366
General Medical Care/ Treatment	1194	141	1335	1487	1707
Occupational/Physiotherapy	534	222	756	832	956
Audiology/Ophthalmology	465	135	600	673	774
Speech/Language Pathology/ Development	210	138	348	396	455
Health Counselling or Promotion	213	198	411	456	523
Home/Personal Care	591	210	801	892	1024
Alternative Therapy/Treatment	162	189	351	396	455

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Anecdotal information provided in Personal Questionnaires by persons with disability suggests that the need for alternative therapy/treatment is driven by

high levels of chronic pain and discomfort, and lack of relief through mainstream/existing services/treatments. While alternative therapy/treatment was not defined, examples given over the course of the Assessment include traditional Aboriginal medicines and healing practices, massage therapy, acupuncture and healing/treatment approaches from other cultures such as Asian cultures.

"*Doctors don't know about Dene medication. They don't understand us elders.*" (from Personal Questionnaire)

Community service providers of mental/physical health services are concerned that there are not enough staff to serve persons with disability and/or their families who need or want occupational therapy, physiotherapy, speech/language pathology/development and alternative therapy/treatment.

"What I need is somebody to help when (I'm) in pain. Some one to help." (from Personal Questionnaire)

Social and Mental Health Services

Most communities in the NWT offer social services through a government agency(ies) or on a project-specific basis through First Nation or community organizations. Like other human services in the NWT, the range of social and mental health services available is proportionate to the size of the population served.

Loneliness and feeling good about themselves are among the daily living problems faced by persons with disability in the NWT. These issues are particularly critical for the young and for the old, regardless of the type of disability they have. (see Figures 19 and 20, pg. 62 and 63) The issues of loneliness, isolation and self-esteem have been raised in a wide variety of NWT

research as key factors in high risk behaviours including suicide, early school leaving and violence.[32]

"Nobody visits me. I can't walk very far. I feel very sad and lonely." (from Personal Questionnaire)

To deal with social and mental health needs, persons with disability in the NWT mainly use personal supports (eg. local support groups). Special equipment/aids such as workshops and resource materials, are the greatest unmet need. (Table 26) The demand for personal supports including personal and family counselling, and special equipment/aids is expected to continue in the future.

As shown in Table 26, the need for addictions counselling and treatment services and alternative therapy is more than double the current use of these services. The demand for alternative services may be due to a lack of success using or accessing mainstream programs. In the case of addictions services, persons with disability may have difficulty accessing these programs due to the closure of treatment/rehabilitation programs in Yellowknife and Inuvik in recent years.

"There are no support groups or special programs for disabled people." (from Personal Questionnaire)

---

[32]Peart, M. and King, A.J.C. January 1996. **Health Behaviours, Attitudes and Knowledge of Young People in the Northwest Territories**. Education, Culture and Employment. GNWT

Table 26: The NWT Demand for Social and Mental Health Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Personal Supports	531	249	780	872	1001
Specialized Intervention/ Program	171	192	363	396	455
Special Equipment, Aids, Tools	393	303	696	773	888
Personal or Family Counselling	189	207	396	436	501
Addictions Counselling or Treatment	63	144	207	238	273
Psychological or Psychiatric Help	135	135	270	297	341
Diagnosis or Assessment	390	186	576	634	728
Referral or Information	333	177	510	535	615
Parenting Support	150	96	246	277	319
Alternative Therapy/Treatment	99	195	294	337	387

Note: *"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Community providers of social and mental health services believe that there are adequate program/service staff to provide referral services for persons with disabilities and their families who want or need these services. However, there are insufficient staff to serve those persons affected by disability who need or want other social and mental health services listed in Table 26. Community service providers see the current demand for psychological or psychiatric help and alternative therapy/treatment as much greater than the capacity of staff to deliver these services.

Accommodation/Housing Services

Accommodation/housing services are available in every community in the NWT mainly through local housing organizations or municipal/First Nation governments. Economies of scale limit housing options in small communities. Housing subsidies are used now and are the greatest unmet need among persons with disabilities in the NWT. Demand for accommodation subsidies are expected to continue in the future. Demand is likely due to low income levels and high unemployment among persons with disability in the NWT.

Persons with disabilities also identify a significant unmet need for help fixing or modifying the home. (Table 27) The extent of this need is almost equal to the number of persons with disability now receiving housing subsidies. This demand

Table 27: The NWT Demand for Accommodation/Housing Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Housing Referral or Information	210	177	387	436	501
Help Fixing/Changing the Home	144	306	450	496	569
Accommodation/Housing Subsidy/Money	330	252	582	654	751
Special Accommodation/Group Home	324	126	450	496	569

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

is consistent with the needs expressed by NWT persons with disabilities for adaptations in the home to help cope with daily living activities. (shown in Tables 15-24, pages 50-58)

Persons with disabilities also indicate a need for special accommodation/group home programs/services. This need may arise from affordability issues or from concerns about loneliness and isolation, two significant daily living problems identified throughout this Needs Assessment.

"Due to illness, I need to be around people I feel comfortable with. I need to live with people not on my own." (from Personal Questionnaire)

Community service providers of accommodation/housing services identify a shortage of staff to provide services to persons affected by disability who need or want them. Providers identify the main service shortfall as special accommodation/group home programs/services.

"I am 89 years old, who will look after my son?" (from Parent/Caregiver Questionnaire)

Housing for persons with disability is not an immediate concern of parents/ caregivers of persons with disability.

- A significant number of parents/caregivers of persons with disability have not considered or do not know where the person they care for would live, should a change in living arrangements be required.
- One-third of parents/caregivers (33%) felt that the person with disability would be cared for by another family member.
- Another one-fifth (20%) expect that the person could move to a community facility.

Lack of contingency planning may pose risks for persons with disability given the

shortage of suitable and affordable housing in most NWT communities.[33]

Income

"Being blind, it's hard because there's not enough $ to take care of myself. How come there's no funding for disabled people?" (from Personal Questionnaire)

'Having enough money' is the main difficulty for persons with disability. Most (80%) persons with moderate to severe disability in the NWT have personal and household incomes below the national poverty level of $20,000. (Figure 8 pg. 34) Only 16% of persons with moderate to severe disability who are 15 or more years of age are employed or run a business. Only a small number of persons with disability have income from a pension or disability benefit. (The Workers Compensation Board provides pensions to 248 persons in the NWT with permanent long term disability.)

"*One year ago I found out I have a condition called Primary Pulmonary Hypertension. I don't know how long I'll be able to work. Haven't paid enough CPP for disability pension. I don't know how I will be funded.*" (from Personal Questionnaire)

"*Because of my condition, I cannot work and the Income Support is not enough to support my children and myself.*" (from Personal Questionnaire)

Next to medical/physical health and social/mental health services, income support is in greatest demand by persons with disability. About 40% of persons with disability use or need income support now. (Table 28) Over half (52%) of adults with disability use, need or will need income support. There is also an unmet need for budgeting and financial information.

---

[33] 1999 NWT Housing Survey

Table 28: The NWT Demand for Financial Assistance in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Income Support, Subsidy or Basic Needs	501	219	720	793	910
Budgeting or Money Management Help	159	186	345	377	432
Financial Info/Advice	75	204	279	317	364

Note: *"Need now" refers to services needed but not received now.
The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

In some communities, the Income Support Program has placed persons with disability on a payroll system, meaning that cheques are issued regularly and sent by mail. This system streamlines services and may contribute to the view of community service providers that financial assistance programs/services listed in Table 28 have adequate staff to serve the people with disability and their families needing or wanting these services.

"Having a program set up specifically for people with disability. We don't have to continuously go to get forms filled out every month." (from Personal Questionnaire)

Life Skills, Employment and Residential Supports

Persons with moderate to severe disability in the NWT between the ages of 15 and 64 identify the main problems faced in daily living as having enough money and finding a job. (see Figure 19, pg. 62) With 61% of persons with moderate to severe disability having less than grade 9 education, opportunities to secure a job

and have enough money to live with dignity are limited. Further, as discussed in sections 3.1 and 3.2 of this report, the unmet need for specialized aids, equipment and supports to enable persons with disabilities to participate in the work place or at school present even more challenges.

"*There is no one in the NT who can teach ASL (American Sign Language)*". (from Personal Questionnaire)

Compared to medical/physical health and social services, fewer persons with moderate to severe disability use life skills training or job supports. The reason for this may be limited availability of these services in communities outside of Yellowknife. The need for these services now is as great or greater than the current use. (Table 29) Information provided in Personal Questions indicates that the demand for life skills training, in-home support and job coaching will continue in the future.

Community service providers suggest that there are adequate staff to provide general personal/family/emotional help to persons with disability and their families needing or wanting this program/service. All other programs/services listed in Table 29 are understaffed to meet demand by persons affected by disability. Paid residential support is severely understaffed to meet the demand for people with disability and their families who want or need this service. The Yellowknife Association for Community Living has lent its expertise to several communities in the NWT (eg. Fort Simpson, Rae-Edzo and Inuvik) in the hope of developing a network of supports for persons with intellectual disabilities. Few of these developmental efforts have resulted in a base of life skills, employment and residential supports in communities outside of Yellowknife. This is mainly due to funding issues.

Table 29: The NWT Demand for Life Skills, Employment and Residential Supports in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1952	Total 2009 Demand n=2276
Paid Residential Support	192	105	297	337	387
Life Skills Training	99	162	261	297	341
In-Home Support/Assistance	156	159	315	357	410
Personal/Family/Emotional Support	189	159	348	396	455
Employment or Job Coaching	84	162	246	277	319
Special Equipment, Aids, Tools	135	126	261	297	341

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Education and Training for Adults

The demand for adult education and training programs/services among NWT adults with moderate to severe disability is similar to life skills,employment and residential supports. (Table 30) Aurora College Community Learning Centres operate in only 11 NWT communities and funding for adult literacy and basic education has diminished significantly in recent years.

Table 30: The NWT Demand for Education and Training Services in 2000, 2004 and 2009 by Number of Adults with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Job Skill Development	96	171	267	297	341
Job Training	114	168	282	317	364
Education Program/ Academic Upgrading	126	198	324	357	410
Individualized Education/ Training Service	87	174	261	297	341
Specialized Speech or Language Services	15	114	129	139	159
Personal or Special Needs Assistance	90	138	228	258	296
Personal or Family Counselling	69	123	192	218	250
Special Equipment, Aids, Tools	87	141	228	258	296

Note:

*"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

The unmet need for adult education and training services is greater than current use. Education program/academic upgrading, job training, job skill development and individualized education/training are the services most frequently used and needed now. (Table 30) According to Personal Questionnaires completed by adults with disabilities, job skill development and job training will likely continue to be required in the future.

Adult education and training programs/services in NWT communities seem to be limited. In communities where these programs are available, waiting lists are long and persons needing basic education may be a lower priority than those with higher levels of education (eg. those who can enter a college-level program). Limited access to education and training programs was perceived by one person with disability as "*schools do not accept disabled people*". In other cases, access is limited by the financial resources available to assist persons with disability to attend adult or post-secondary education and training programs.

"Sometimes (it is) hard for me to read and difficult to get help. Have to go to income support. Want to learn how to read and write. Frustrated about things (and) get angry." (from Personal Questionnaire)

Community service providers believe that adult focussed education and training programs and services are severely under-staffed. Persons completing the Community Service Provider Questionnaire reported that virtually all of the services listed in Table 30 except for the provision of special equipment, aids and tools, have one-third to one-half of the staff needed to respond to the demand for adult education and training among persons affected by disability.

Education and Training for Children and Youth

This Needs Assessment provides limited information on children with disability. An assessment of student needs in NWT classrooms undertaken by the GNWT Department of Education, Culture and Employment in 2000, will provide more comprehensive information on program and service needs among school-age children with disability.

This Needs Assessment found that the main problems faced by children (0-14 years) with moderate to severe disability are related to self-esteem/feeling good about themselves and to getting a diagnosis/assessment. (Figure 19, pg.62)

Among the small number of school aged children with moderate to severe disability who participated in this Assessment, the unmet need for education and training services is similar to current use. (Table 31) Those services used and needed now are personal help in the classroom, an individualized education plan (IEP) and/or specialized speech or language services. There is also an unmet need for personal counselling, school readiness or other preschool programs and special equipment. Information provided in Personal Questionnaires indicates that the demand for IEPs and personal counselling is expected to continue into the future.

Table 31: The NWT Demand for Education and Training Services in 2000, 2004 and 2009 by Number of Children/Youth with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
School Readiness/Other Preschool Program	90	66	156	178	205
Individualized Education Plan	108	90	198	218	250
Specialized Speech or Language Services	102	90	192	218	250
Personal or Special Help in the Classroom	142	111	253	277	319
Personal Counselling	72	99	171	198	228
Special Equipment, Aids, Tools in School	69	99	168	178	205

Note: *"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Community service providers identify a severe shortage of staff to serve children/ youth with disability who need or want education and training programs. Special speech and language services are seen as severely understaffed. Speech and language difficulties are major barriers to participation in work, school, social and recreational activities.

Legal Services

This Assessment found that NWT communities are concerned about the lack of services for and/or recognition of brain-related disabilities and the impacts to the individual and the legal system. Persons with these disabilities may be unable to assess the consequences of certain actions and find themselves in conflict with the law. Few persons with disability participating in this Needs Assessment use or need legal services. (Table 32)

Table 32: The Demand for Legal Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Probation Supervision	12	9	21	20	23
Placement Services	15	30	45	59	68
Community Justice/ Local Supports	16	39	55	59	68
Legal Aid	48	48	96	99	114
Mediation, Negotiation, Advocacy	96	57	153	178	205

Note: *"Need now" refers to services needed but not received now. The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Mediation/negotiation and legal aid are services most frequently used and needed now. In data collected on 'other' programs/services (Table 34), the

Needs Assessment found that use of guardianship/trusteeship or supported decision-making services is also high.

In most cases, community service providers believe that legal programs/services are adequately staffed to meet the needs of persons affected by disability who need or want the services listed in Table 32. Information provided in the Community Service Provider Questionnaire indicated a shortage of staff to provide placement services to persons affected by disability.

Protection Services

In a discussion of children in care, the 1999 NWT Health Status Report states that "*many of these children have behavioural problems which may be the result of developmental delays, FAS/FAE, poor parenting skills or general neglect. Other children may come into care because they are being abused. Others may come into care because their parents are receiving alcohol or drug treatment.*"

The Needs Assessment found that compared to other services the number of persons with disability of all ages who use or need protection services, is relatively small. (Table 33) This seems to contradict the high rates of children coming into care, many with disability, reported in the GNWT's Health Status Report (1999). Low participation of children and youth may explain the small demand for protection services identified in this Assessment.

M[illegible]ion/negotiation and emergency care are the most frequently used protection services. Emergency care or shelter services are needed most. Community providers of protection services listed in Table 33 say that these services are understaffed to meet the demand of persons affected by disability. Victim's services are severely understaffed.

Table 33: The NWT Demand for Protection Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Emergency Care or Shelter	75	78	153	178	205
Placement Services	48	60	108	119	137
Victims' Services	21	54	75	79	91
Mediation, Negotiation, Advocacy	132	54	186	198	228

Note: *"Need now" refers to services needed but not received now.
The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

Other Programs and Services

"Having this disability and living in the north I feel discriminated against with very little services." (from Personal Questionnaire)

A variety of "other" programs and services targeted at persons with disability are available in larger NWT communities such as Yellowknife and Fort Smith. Few other NWT communities have programs/services for persons with disability. This is a major concern of persons with disability, as expressed by two persons with disability in Aklavik. "*There are no special needs/services for disabled in the community.*" "*I have to fly out of town to get services.*" (from Personal Questionnaires completed by two Aklavik residents with disability)

Holman is one small community which has given priority to persons with disability. The municipal council in that community has purchased a handivan to assist persons with disability to live independently and to participate in the community. The Holman Community Council has also endeavoured to ensure that

all public buildings in the community are wheel-chair accessible.

Among 'other' services available guardianship/trusteeship or supported decision-making, transportation services, and general information/referral/support services have the greatest use now among persons with disability. (Table 34) The greatest unmet need and expected demand in the future are for transportation (eg. handivan services), advocacy and disability awareness/education services. These

Table 34: The NWT Demand for Other Programs and Services in 2000, 2004 and 2009 by Number of Persons with Moderate to Severe Disability

Program/Service	Use Now	Need Now*	Total 2000 Demand n=1780	Total 2004 Demand n=1982	Total 2009 Demand n=2276
Disability Awareness/Education	84	255	399	436	501
Respite	75	147	222	238	273
Mobility Supports (eg.seeing eye dog)	63	60	123	139	159
Transportation Services	324	324	648	714	819
Special Parking Program	117	75	192	218	250
Equipment/Technical aids/Tools	240	195	435	476	546
Advocacy to Get Services	216	255	471	515	592
General Information/ Referral/Support	312	198	510	575	660
Recreation/Social Activities	282	213	495	555	637
Translation/Interpretation	180	147	327	357	410
Guardianship/Trusteeship/Support Decision-Making	327	105	432	476	546

Note: *"Need now" refers to services needed but not received now.

The Needs Assessment involved one-third of the estimated 1,780 persons with moderate to severe disability. The total demand for programs/services in 2000 is three times that identified in the Needs Assessment. The demand for programs/services in 2004 and 2009 assumes the same ratio of demand as in 2000.

needs are particularly great in smaller communities where there are virtually no specialized services for persons with disability. The need for disability awareness/education, respite and advocacy for services outstrips the current use. According to community service providers, not one of the programs and services listed in Table 34 is adequately staffed to meet the demand for these services by persons affected by disability. Two programs/services which are significantly understaffed are disability awareness/education and special parking programs.

4.2 Program/Service Needs of Parents/Caregivers of Persons with Disability

Parents/caregivers of persons with disability participating in this Assessment care mainly for children (0-14 years) and adults (15-64 years of age) with known, moderate to severe disability. Over one-third care for persons with multiple disabilities and about half provide 24 hour care/supervision. Parents/caregivers encounter significant personal and other challenges in giving care (as illustrated Figures 22 and 23, pg. 67). These challenges are exacerbated by an overall lack of program/service support for caregivers in the NWT. The lack of programs/ services and recognition of the role of parents/caregivers are major sources of frustration for caregivers. This frustration was expressed in completed Parent/Caregiver Questionnaires.

"Its hard to care and help with so few services/programs."

"There are no resources/programs for people with disability."

"How do we as parents come to terms with what has happened to cause the disability? How do we cope with what the present and the future may bring if things stay as they presently are?"

"I really want my son to live with me at home but no resources are available in the region. At the same time I want what is best for him (I have) no options."

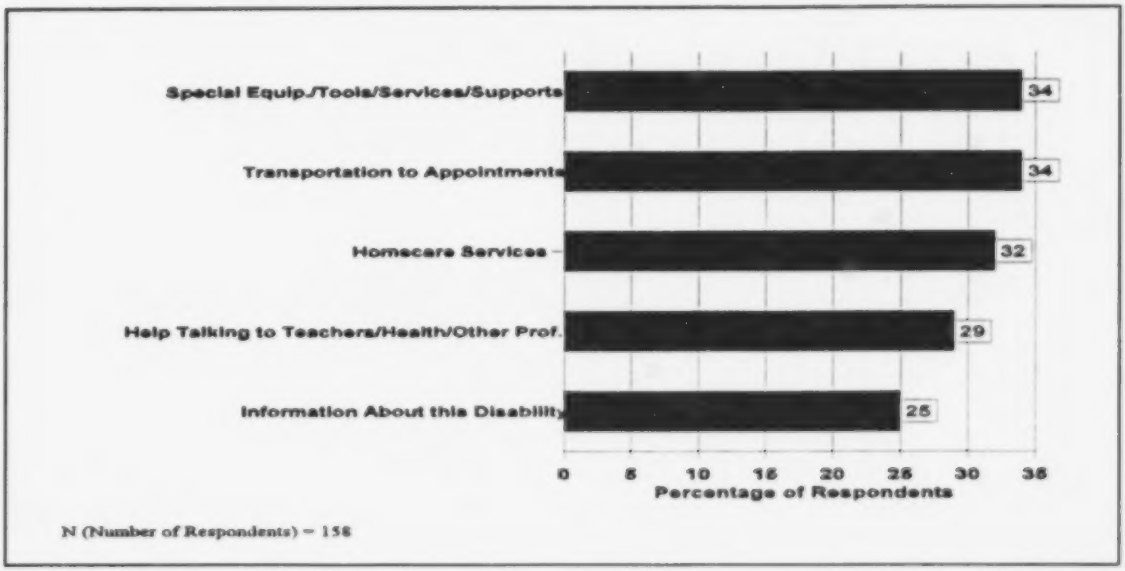
"There is no extra help for special needs children in any way, shape or form. From money to learning aids that the specialists recommend. For two years I have been fighting to get my son the learning aids he requires. I have now given up hope."

"Do I get any money for caring for my spouse? NO"

"You need an advocate, case manager, advice on funding and procedures to procure $$."

To help parents caregivers give care, special equipment/supports and transportation to get to appointments are the two programs/services most frequently used. (Figure 25) As noted elsewhere in this report, these programs/services are not widely available in NWT communities. Special equipment/supports also may not be available to persons within their own homes. *"Providing special aid/support and home caring services. Learning tools (should) be accessible to (in the) home. Training and learning tools (should be available) for home use."* (from Parent/Caregiver Questionnaire)

Figure 25: Programs and Services Used by Parents/Caregivers of Persons with Disability, NWT Needs Assessment 2000



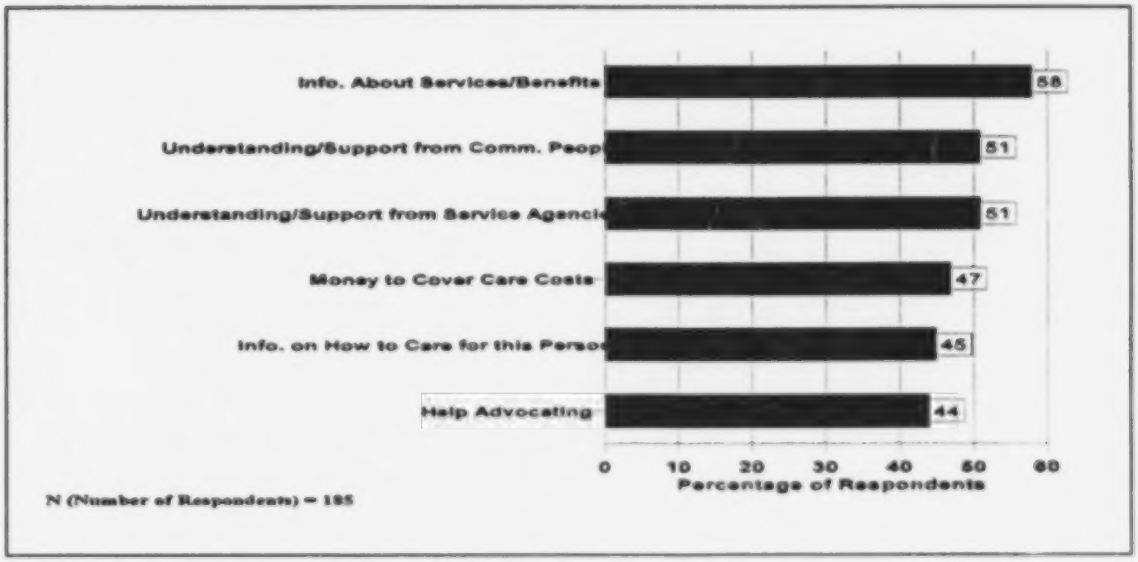
Parents/caregivers of persons with disability identify a wide range of unmet needs. Information, understanding, support and financial resources are needed most. (Figure 26)

Numerous comments were made in the Parent/Caregiver Questionnaire about programs/services to care for and offer respite to caregiver. At the same time, respite was not identified as an unmet need by parents/ caregivers of persons with disability. (Figure 26) There may be many reasons for this, including an unwillingness/shyness about asking for help or a break, lack of understanding of the term, or fear for the safety and well-being of the person.

"This person should be encouraged to stay somewhere where he is cared for while I can take a break."

"(I) Need respite care badly. I can't leave Mom. (My) Brothers won't help."

Figure 26: Programs and Services Needed by Parents/Caregivers of Persons with Disability, Needs Assessment 2000



It is likely that the needs of parents/caregivers could be met through widespread respite, counselling, advocacy and caregiver benefit programs.

"No financial help or training because he is a family member. Should consider training and paying family instead of others. Could be more a part of family, culture and community this way." (from Parent/Caregiver Questionnaire)

4.3 Delivering Appropriate Programs and Services to Persons Affected by Disability

Community service providers in the NWT encounter a wide variety of challenges to delivering appropriate programs/services to persons with disability. These challenges are made more difficult by high staff turn-over, large caseloads, poor

understanding of disability, and lack of opportunities to work and share information with other service providers. While there was little consensus on the greatest challenges faced by community service providers participating in the Needs Assessment, most frequently identified were:

- inadequate financial resources (37%).
- inadequate numbers of staff (33%).
- lack of community programs/services (32%).
- inadequately trained staff (28%).

"*Burn out is a danger in this job especially considering the inability of Social Services to provide much support.*" (from Community Service Provider Questionnaire)

The vast majority (79%) of persons with moderate to severe disability living in households in the NWT, have Aboriginal ancestry. About two-thirds of community service providers participating in the Needs Assessment consider their programs/ services to be culturally relevant to persons with disability in the NWT. Service providers in NWT communities must overcome tremendous barriers to deliver culturally relevant programming. The most significant of these are:

1. difficulties hiring/retaining qualified staff fluent in the Aboriginal language(s) of the community.

"(Difficult to hire) *Interpreters with sound medical knowledge and excellent grasp of both English and Native language.*" (from Community Service Provider Questionnaire)

2. access to culturally relevant materials, activities, and programs.

"*material is not culturally relevant and assessment tools (are) not made for Aboriginal people.*" (from Community Service Provider Questionnaire)

"*Program does not consider alternative medicine.*"(from Community Service Provider Questionnaire)

3. limited awareness or understanding of the culture and lifestyles of the community.

"*Cross cultural workshops are needed to provide non-Aboriginal people with an understanding of the people.*" (from Community Service Provider Questionnaire)

"*Lack of knowledge of (Aboriginal) culture. Lack of normative studies of (the) northern population.*" (from Community Service Provider Questionnaire)

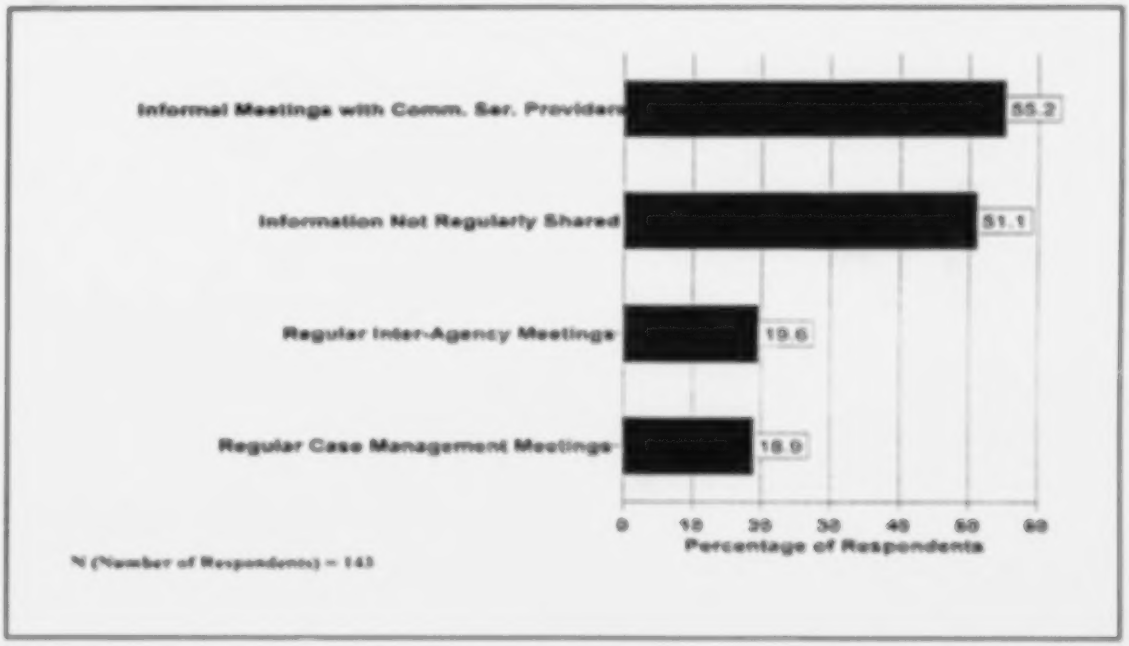
4. lack of community support.

"*social-economic barriers effect service delivery.*"(from Community Service Provider Questionnaire)

"*Unrelated caregivers (are) reluctant to do personal care and client(s) (are) reluctant to have strangers provide it.*" (from Community Service Provider Questionnaire)

While inter-agency collaboration and case management are principles of many social programs in the NWT, less than one-fifth of community service providers apply these principles to addressing disability issues and needs. At best, information sharing among service providers at the community level is informal. Over half of the community service providers participating in this Assessment say that information is not regularly shared. (Figure 27).

Figure 27: Information Sharing on Disability Issues and Needs by Percent of Community Service Providers, NWT Needs Assessment 2000



In this Needs Assessment, persons with disability were asked whether programs and services meet their cultural needs. Most (63%) believe that programs/ services do not meet their cultural needs or their needs in general. Anecdotal comments offered by persons with disability suggest four main reasons for this view:

1. General lack of understanding, support and recognition of disability.

"*Politically no one is representing the disabled people.*" (from Personal Questionnaire)

"*There are no services for the disabled in this community, no advocacy.*"(from Personal Questionnaire)

2. Lack of awareness of and sensitivity toward Aboriginal languages and customs.

"Everything is more directed at (the) non-Aboriginal way of life."(from Personal Questionnaire)

"I can't trap and spend time in the bush. I would like to do that but no program allows me to."(from Personal Questionnaire)

"Need qualified medical interpreter/translator and more interaction with the elders and qualified staff/homecare."(from Personal Questionnaire)

3. Lack of access to services in the (home) community.

"We need more programs and services HERE."(from Personal Questionnaire)

4. Lack of care and attention by community and service providers. (from Personal Questionnaire)

"No one asks me what I need". (from Personal Questionnaire)

"Programs and services are kept secret -disabled people are usually the last to know." (from Personal Questionnaire)

Persons with disability describe five main ingredients of programs/services which meet their needs, including their cultural needs.

1. A sense of peace and security within their environment.

"I am happy with this home setting and what this program has to offer me." (from

Personal Questionnaire)

2. Support to participate in community events, particularly cultural activities.

"I am encouraged to attend any cultural events whenever possible and enjoy traditional foods." (from Personal Questionnaire)

3. Access to country foods and help with such activities as sewing, drying meat, and getting ice.

4. The ability to receive services in one's own community.

"*The service provided by home care and by my family is all I need at this time.*" (from Personal Questionnaire)

5. The availability of Aboriginal language speakers.

"*Yes, I believe these services and programs meet my needs but I often am lonely.*" (Personal Questionnaire)

Other elements of appropriate programs/services for persons with disability were cited as: the quality, understanding and sensitivity of caregivers and placements; and the availability of a handivan/special transportation in the community.

4.4 Programs and Services Best Practices

Community service providers offered examples of programs/services which have assisted people with disability. Many of these examples are drawn from larger communities, particularly Yellowknife, and from non-government organizations.

These examples may provide some guidance for future programs and services for persons with disability.

- Programs which focus on advocacy for the person with disability and his/her parent/caregiver and collaboration among various groups. Programs/services offered by the following organizations were cited as examples: the Yellowknife Association for Community Living, the NWT Council for Disabled Persons, Chartrand Group Home, Yellowknife Womens' Centre, Tree of Peace, Project Change/Learning Centre, Salvation Army, CNIB, and Canadian Hard of Hearing Association.

- Homecare programs, in-home support, home visits, "meals on wheels" and outreach programs which provide much needed help as well as reduce the isolation and loneliness that persons with disability may feel.

- Day programs which stimulate persons with disability including literacy, adult education, fitness and healing programs, and enable participation and contribution to the community.

- Early intervention programs which enable early detection and development of skills/techniques to cope with disability.

- Rehabilitation services including the loan of equipment/tools/aids.

- Respite and supports for caregivers.

- Transportation services and adaptations to facilitate access in the community.

5. Recommendations to the Needs Assessment Partners

Persons with disability, parents/caregivers of persons with disability and community service providers contacted over the course of this Needs Assessment expressed a high degree of scepticism about the will of government, other organizations, communities, families and individuals to address the issues that will enable persons with disability to live with dignity. Implementing the following recommendations will demonstrate that the will is there to work toward this goal.

1. It is recommended that the partners sponsoring this Needs Assessment, use the findings to plan appropriate programs and services for persons affected by disability in the NWT.

2. It is recommended that the partnership established for this Needs Assessment continue to function, in order to ensure that appropriate programs and services for persons affected by disability are implemented throughout the NWT.

3. It is recommended that the partnership established for this Needs Assessment communicate the findings and intended actions to the general public.

4. It is recommended that the responsibility for disability within the Government of the NWT be clearly identified and communicated to the public.

5. It is recommended that those factors limiting collaboration in this Needs Assessment be addressed by the partners both in the example that they set and the message that they send to service providers and organizations delivering programs/services/supports to persons affected by disability.

6. It is recommended that the Needs Assessment partners begin discussions with the GNWT Department of Education, Culture and Employment, Early Childhood and School Services to identify complementary approaches to addressing the needs of children/youth with disability and their parents/caregivers, as identified in this Needs Assessment and the ECE's Student Needs Survey.

7. It is recommended that the lessons learned from this Assessment be applied to Phase 2 research into psychiatric disabilities.

APPENDIX A: TERMS OF REFERENCE

TERMS OF REFERENCE

PROJECT TITLE:

Needs Assessment of Persons with Disabilities in the western Northwest Territories (NWT)

BACKGROUND:

A needs assessment of persons with disabilities in the western NWT would be valuable for future program and service planning for people with disabilities. There are many gaps in current services for people with intellectual, sensory and physical disabilities. These needs include but may not be limited to: health care, social services, education, training, employment, housing, residential support, respite care and income support.

A Project Working Group will oversee this project. It includes representatives from the Government of the Northwest Territories Departments of Health and Social Services and Education, Culture and Employment, the N.W.T. Council for Disabled Persons and the Yellowknife Association for Community Living.

PURPOSE:

The purpose of this needs assessment is to identify the numbers of persons with intellectual, sensory and physical disabilities in the western NWT, identify existing services and the need for additional services required to ensure that the needs of persons with disabilities and their families in western NWT communities are met. This will enable effective and appropriate resource planning and development of programming for this target group.

SCOPE OF THE PROJECT:

- Compile existing quantitative and qualitative information on individuals with disabilities in the western NWT to: identify the number and percentage of the western territorial population with sensory, intellectual and physical disabilities; the nature and distribution of these disabilities; day to day living needs by main type of disability; existing services available in communities; issues faced by persons with these disabilities and their families; and, current and projected (5-10 years) service needs.

- Develop and administer a survey instrument to capture the above information which is not already available.

- Establish an information base for each western NWT community identifying the number and percentage of the western territorial population with sensory, intellectual and physical disabilities; the nature and distribution of these disabilities; day to day living needs by main

type of disability; existing services; issues faced by persons with these disabilities and their families; and, the current and projected (5-10 year) service needs.

- Consult with individuals with various types of disabilities and existing government and non-government service providers to assess current and projected service needs in various types of western NWT communities for various types of disabilities.

- Prepare a report and data base compiling the data and other information collected for review by the project working group which includes appropriate options for meeting needs of persons with disabilities.

- Persons with mental illnesses, including depression, schizophrenia, panic disorders, etc., and service gaps for this population will not be included in this needs assessment.

PROJECT OUTPUTS:

- A data base which allows access to community-based information on numbers of persons with sensory, intellectual and physical disabilities, the nature of disabilities, existing services, and current and projected gaps in services. Confidentiality of individuals will be protected.

- A report on findings including options for the delivery of services to persons with disabilities. Confidentiality of individuals will be protected.

- All backup documentation, survey and interview results and data base gathered through the project will be the property of the working group and are to accompany the final report with anonymity of stakeholders protected.

PROJECT TIMEFRAME:

Project to be completed by March 31, 1999.

RELATIONSHIPS:

The contractor will report to the Disability Needs Assessment Project Working Group. This working group will support and provide input into the project. At the outset definitions of sensory, intellectual and physical disabilities will be provided.

The active participation of regional health and social service boards and education boards, and their respective community staff, is critical to the success of this project and will be actively advocated by the Departments of Health and Social Services and Education, Culture and Employment.

SKILLS AND EXPERIENCE REQUIRED BY THE CONTRACTOR:

- research and analytical skills
- survey tool development skills
- organizing data into a comprehensive, readable format (report writing) and data base
- related experience
- sensitivity to northern issues

PROPOSAL RESPONSE GUIDELINES:

All proposals shall be received by **4 p.m. January 8, 1999** and include the following information:

1. Approach and methodology options for completing the project.

2. Proposed alteration to request time frame if unable to provide as estimated.

3. A detailed time frame for each data collection stage and the final written report.

4. Resumes of all personnel to be attached to the project, including descriptions of experience relevant to this proposal call.

5. Two references.

6. Fee and expense estimates with explanation, including person/hour estimates, per diem rates and travel and accommodation expenses where applicable.

PROPOSAL EVALUATION CRITERIA:

1. Cost within available budget range.

2. Workplan and schedule within timeframe.

3. Relevance of qualifications and past experience to this proposal.

4. Methodology demonstrates understanding of project.

5. Project team.

Submit proposals to:

N.W.T. Council for Disabled Persons
Centre One Building, 5013 48th Street
Yellowknife, NWT X1A 2P1
Fax: 867-873-4124
Phone: 867-873-8230

APPENDIX B: NEEDS ASSESSMENT OF PERSONS WITH DISABILITY CHRONOLOGY

NEEDS ASSESSMENT OF PERSONS WITH DISABILITIES - CHRONOLOGY

Background

1997	Formation of H&SS/NGO working group on disabilities
November 4, 1997	Preliminary research instrument
August 1998	Regrouping of disabilities working group. ECE joins
December 22, 1998	Call for proposals
January 8, 1999	Proposal call closes

Phase 1: Research Design

January 22, 1999	Needs Assessment Partners Meeting #1[1] (parameters, outcomes, information sources, partner responsibilities and regional contacts)
January 29,1999	Needs Assessment Partners Meeting #2 parameters, desired outcomes and communications)
February 8, 1999	Introductory letter to regional education, health and social service boards
March 1,1999	Needs Assessment Partners Meeting #3 (parameters, definitions and instrument development)
March 8, 1999	Needs Assessment Partners Meeting #4 (instrument development)
March 14, 1999	Revised instruments for review by partners
March 17, 1999	Five test instruments sent to Bureau of Statistics for review
March 19,1999	Needs Assessment Partners Meeting #5 (refinement of instruments with partners and H&SS statistician)
March 19 - 31,1999	Testing instruments in Rae-Edzo and Yellowknife
April 1,1999	Needs Assessment Partners Meeting #6 (review of test results with H&SS statistician)
April 9, 1999	Needs Assessment Partners Meeting #7 (involvement of schools)
April 13,1999	H&SS info and request for participation letter to Health Boards CEOs
April 19 - June23,1999	Negotiations with Early Childhood and School Services
April 22,1999	Draft final research instruments
April 28, 1999	Needs Assessment Partners Meeting #8 (address ECE-EC&SS negative reaction to Assessment)
May 18,1999	Needs Assessment Partners Meeting #9 (negotiation with EC&SS - partners rethink inclusion of psychiatric disabilities)

[1]The average duration of each Partners Meeting was 3 hours.

May 21,1999	Meeting with D. Bower of YACCS regarding proposed Cognitive Impaired Needs Assessment
June 23,1999	Needs Assessment Partners Meeting #10 (EC&SS ECE decides not to participate in the Assessment)
July 29,1999	Metis Nation -NWT advertise for Disabilities Opportunities Coordinator
August 10,1999	Needs Assessment Partners Meeting #11 (finalize newsletter and questionnaires for printing)

Phase 2: Field Work

August 17,1999	Gary Bohnet, President of the Metis Nation agrees to join the partnership
August 18,1999	Needs Assessment Partners Meeting #12 (promo strategy, identification of additional funding to meet project costs)
August 18, 1999	Partners' letter updating regional boards/agencies on status of the Assessment
September 13,1999	Questionnaires go into the field in Yellowknife and regional scoping begins
September/October	ECE's EC&SS directs Regional DEC's not to talk to the Lutra research team or participate in regional scoping
September 30,1999	Stanton Regional Hospital expresses disappointment of not participating as a partner
October 6-12,1999	Determine protocol for EC&SS involvement in Assessment
October 8,1999	H&SS HQ and Lutra teleconference with W. Drodge, CEO Hay River to address methodological issues
October 8,1999	NWTCDP seeks partners input on budget for HRDC funding
October 20, 1999	ECE EC&SS letter to all schools/principals requesting limited participation in the Council's Assessment, ignoring the multi-sector partnership
October 26,1999	Review Metis Nation field support with concerns about lack of field reports. Metis Nation wants more/higher profile in Assessment
October 31,1999	All regions involved in Assessment except Deh Cho and North Slave/Dogrib Region
November 1, 1999	Needs Assessment Partners Meeting #13 - status report
November 8,1999	Dogrib Community Services Board - understaffed and reluctant to participate
November 8,1999	Partners/HRDC Conference call to discuss resources for completing data collection
November 8,1999	First recorded incidence of front-line worker being verbally abused due to exclusion of psychiatric disability
November 9,1999	MaryAnne Duchesne submits Guest Editorial to 'News/North'

November 10,1999	H&SS contemplates sending HQ staff into the regions to promote the Assessment
November 15,1999	Meeting between Independent Clubhouse and some Needs Assessment Partners regarding exclusion of psychiatric disabilities
November 16,1999	Needs Assessment Partners Meeting #14 (data compilation logistics)
November 16,1999	H&SS proposes phase two of the Assessment to engage persons with psychiatric disabilities within a broader mental health framework
November 8-26,1999	H&SS fielding concerns from Boards regarding consistency of data, validity, resources, methodology and manner Boards have been engaged in the Assessment
November 19,1999	Project overview developed to answer H&SS Board questions
November/December	Open Houses at Baker Centre and the NWT Council for Disabled Persons
December 8,1999	Metis Nation withdraws from Needs Assessment partnership
December 9, 1999	HRDC approves funding to complete data collection
December 17, 1999	Needs Assessment Partners Meeting #15 (status report)
January/February, 2000	Open Houses at Salvation Army, Aurora College, Yellowknife Correction Centre

Phase 3- Data Compilation, Analysis and Reporting

January 31,2000	Needs Assessment Partners Meeting #16 (status report and reporting framework)
March 13,2000	Yellowknife Focus Group
March 27,2000	Fort Smith Focus Group
April 17, 2000	Submission of draft methodological and findings reports
April 18, 2000	Partners and stakeholders workshop to review draft reports
April 28- May 12,2000	Partners provide feedback on draft reports
June 7,2000	Submit five community reports
June 8, 2000	Circulate popular summary for Partner's review
June 23,2000	Submit final draft methodological and findings report

APPENDIX C: NEEDS ASSESSMENT QUESTIONNAIRES AND NEWSLETTER

NEWS BULLETIN

A Needs Assessment of Persons with Disabilities in the NWT

A disability is any degree of physical, sensory, psychiatric, cognitive, intellectual or learning limitation which causes difficulty in the usual activities of daily living. No one knows for sure how many people in the NWT have a disability or the type of disability they have. We don't know how these disabilities affect day to day living. We don't know what kinds of programs and services are needed so people with disabilities have equal opportunity to participate in community life. The goal of this Needs Assessment of Persons with Disabilities is to answer these questions. **To achieve our goal, this Assessment needs to hear from people with disabilities, their families and front-line workers.**

The information gathered in this Needs Assessment will lead to:

- more understanding of disabilities and about living with a disability.
- more recognition of and discussion about disabilities in the NWT.
- better programs/services for people with disabilities and their families.

This Assessment will not name anyone or give any information that would enable anyone to be identified.

The people who are working together to do this Needs Assessment have direct experience with disabilities. They are:

- **NWT Council for Disabled Persons**
- **YWCA of Yellowknife**
- **Metis Nation of the NWT**
- **GNWT Education, Culture & Employment** (College & Careers Division)
- **Yellowknife Association for Community Living**
- **GNWT Health & Social Services**
- **MaryAnne Duchesne** (self-advocate)

Aggie Brockman, the Executive Director of the **NWT Council for Disabled Persons**, is the contact person. You can phone her at (867) 873-8230 or contact her by fax (867) 873-4124 or by e-mail at disabilitynwt@tamarack.nt.ca

Assessing the Needs of Persons with Disabilities is Challenging.

Many people are surprised to learn that no complete information is available on disabilities in the NWT. There are many different reasons for this, for example:

- an unwillingness to draw attention to, or talk about disabilities.
- fear of negative attitudes or discrimination.
- the possibility of cultural misunderstanding leading to a wrong diagnosis.
- lack of training or the right tools to assess or diagnose disabilities.
- the high cost of diagnosis and assessment.

About the Needs Assessment of Persons with Disabilities.

This Needs Assessment is being done in all 33 communities in the NWT. Nunavut communities are not involved. This Assessment:

- involves people with disabilities of all ages.
- includes people with disabilities no matter where they live or whether they receive services or not.
- collects information on physical, sensory, cognitive, intellectual and learning disabilities. **Psychiatric disabilities or illnesses are <u>not</u> included in this Assessment <u>except</u> where present with another disability.**

The Assessment should be finished by **December 31, 1999.**

Lutra Associates Ltd. in Yellowknife have been contracted to coordinate this Needs Assessment. **Sandy Auchterlonie, Lois Little and Bob Stephen** at Lutra are the people working on this project. They can be contacted at (867) 920-2177 or by fax at (867) 873-8368 or by e-mail at xlutra@ssimicro.com

The Needs Assessment has five parts:

1. **Personal interviews** in regional centres with government and non-government agencies which provide services/programs to people with disabilities. These interviews will be done by Lutra Associates Ltd.

2. A **Community Service Provider Questionnaire** about the services that front-line workers provide to people with disabilities. Lutra will provide telephone assistance to help front-line workers complete the Questionnaire.

3. A **Personal Questionnaire** to be completed by people who have a disability. Community Service Providers will be asked to help people complete the Questionnaire and telephone assistance will be provided by Lutra Associates.

4. A **Parent/Caregiver Questionnaire** to be completed by the parents/ caregivers of people with disabilities. Community Service Providers will be asked to help people to complete the Questionnaire and telephone assistance will be provided by Lutra Associates.

5. **Focus groups** in three communities to confirm and refine research findings.

The Early Childhood and School Services Division of the GNWT Department of Education, Culture and Employment will be visiting NWT schools to conduct a survey to identify the support needs of all students. This survey will update information collected by the Department in 1993. The groups involved in this Needs Assessment and staff from Early Childhood and School Services are exploring ways to share information between the two projects.

Definitions Used in this Needs Assessment

A disability is *any degree of physical, sensory, cognitive, intellectual, learning or psychiatric limitation which causes difficulty in the usual activities of daily living.* Psychiatric disabilities/illnesses are not included in this Needs Assessment except in cases where they may be present along with another disability. The disabilities are defined as follows.

Physical Disability

A physical disability involves a significant loss of mobility, agility, strength, flexibility or coordination. Some conditions which involve physical disabilities are paraplegia, quadriplegia, amputation, cerebral palsy, polio, multiple sclerosis and arthritis.

Sensory Disability

A *sensory disability involves the senses.* Sensory disabilities include: blindness or significant vision loss, deafness or significant hearing loss, the inability to speak, and a lack of balance from disorders such as Vertigo or Meniere's Disease.

Cognitive Disability

A *cognitive disability is usually a degenerative condition that affects the brain's ability to process information.* It is not present from birth. Cognitive disabilities may include Alzheimer's, senility and late stage alcoholism.

Intellectual Disability

An *intellectual disability impacts the rate at which a person develops, learns and/or remembers.* This disability is usually present from birth. People with intellectual disabilities may have Down's Syndrome, traumatic brain injury, fetal alcohol syndrome, alcohol-related birth defects or other undefined disabilities.

Learning Disability

A *learning disability affects the way people with average or above average intelligence take in, process or express information.* Learning disabilities are permanent, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social skills, emotional maturity and coordination.

A Needs Assessment of Persons with Disabilities in the NWT - Community Service Provider Questionnaire

Have you read the August News Bulletin describing the Needs Assessment?

The **Community Service Provider Questionnaire** is one of three questionnaires being completed as part of the Needs Assessment of Persons with Disabilities. The other two questionnaires are the **Personal Questionnaire** to be completed by persons with disabilities, and the **Parent/Caregiver Questionnaire** to be completed by those who care for people with disabilities.

A Community Service Provider *is someone who has personal contact with and delivers programs/services directly to people with disabilities and/or their families/caregivers.* In most cases, a Community Service Provider is a paid person although some volunteers may also provide programs/services to people with disabilities and/or their families. People who are employed to provide residential or employment supports to people with disabilities are also Community Service Providers.

Community Service Providers can have many different job titles but most often they are:

•	Alcohol and Drug Workers	Home Care Workers	Social Workers
•	Community Support Workers	Community Health Representatives	RCMP officers
•	Tenant Relations Officers	Legal Aid Workers	Nurses
•	Child Care Workers	Income Support Officers	

All Community Service Providers are being asked to complete a **Community Service Provider Questionnaire.** If you share responsibilities for a particular program or service, please work with your co-workers to complete this Questionnaire. This avoids duplication and helps to collect the best possible information.

Please ensure that individuals are not identified by name and that all other information about each person with a disability is kept confidential.

The **Community Service Provider Questionnaire** collects information on each service/ program which is provided directly to people with disabilities and/or their families. As a Community Service Provider, you may deliver many services and programs. A separate **Community Service Provider Questionnaire** should be completed for each program or service delivered. For example, Income Support Officers provide financial assistance directly to people with disabilities and/or their families. They may also advocate directly on behalf of individuals who have a disability and/or their family/caregiver. The Income Support Officer would complete one questionnaire for direct financial assistance services and one questionnaire for direct advocacy services. Services that are not provided directly to individuals with disabilities/families such as policy, planning or general advocacy for all disabled persons should not be reported in a **Community Service Provider Questionnaire**.

Depending on the completeness of your own records, it should take about two hours to do the **Community Service Provider Questionnaire**.

Once the **Community Service Provider Questionnaire** is done, the next step is to invite people with disabilities to complete a **Personal Questionnaire** and to ask their families to do a **Parent/Caregiver Questionnaire**. Community Service Providers are being asked to distribute these Questionnaires and if need be, help to complete them. By working with other Community Service Providers, we hope that people with disabilities receive only one **Personal Questionnaire**, and the parents or the main unpaid caregivers of people with disabilities receive only one **Parent/Caregiver Questionnaire.**

People with disabilities and their families/caregivers may receive services/ programs from more than one agency. Please contact colleagues in other helping agencies to look at ways to ensure that everyone affected by a disability is invited and helped to participate.

The success of this **Needs Assessment of Persons with Disabilities** depends on YOU, the Community Service Provider.

The Needs Assessment Partners know that Community Service Providers are very busy. We greatly appreciate your time and help. We will recognize your efforts in the final report and give you a small gift as a token of our appreciation.

Lutra Associates Ltd. has been contracted to coordinate the Needs Assessment and they will be in touch with Community Service Providers regularly to give assistance and support. Or you can contact Sandy Auchterlonie, Lois Little or Bob Stephen at Lutra at any time. Contact Sandy, Lois or Bob at Lutra at (867) 920-2177 or by fax (867) 873-8368 or via e-mail at xlutra@ssimicro.com

Please complete the Community Service Provider Questionnaire within one (1) month of receiving it. All completed questionnaires should be returned to Lutra Associates Ltd., Box 1866, Yellowknife, NT XIA 2P4.

Definitions Used in this Needs Assessment

A disability is *any degree of physical, sensory, cognitive, intellectual, learning or psychiatric limitation which causes difficulty in the usual activities of daily living.* Psychiatric disabilities/illnesses are not included in this Needs Assessment except in cases where they may be present along with another disability. Specific disabilities are defined as follows.

Physical Disability

A physical disability involves a significant loss of mobility, agility, strength, flexibility or coordination. Some conditions which involve physical disabilities are paraplegia, quadriplegia, amputation, cerebral palsy, polio, multiple sclerosis and arthritis.

Sensory Disability

A *sensory disability involves the senses.* Sensory disabilities include: blindness or significant vision loss, deafness or significant hearing loss, the inability to speak, and a lack of balance from disorders such as Vertigo or Meniere's Disease.

Cognitive Disability

A *cognitive disability is usually a degenerative condition that affects the brain's ability to process information.* It is not present from birth. Cognitive disabilities may include Alzheimer's, senility and late stage alcoholism.

Intellectual Disability

An *intellectual disability impacts the rate at which a person develops, learns and/or remembers.* This disability is usually present from birth. People with intellectual disabilities may have Down's Syndrome, traumatic brain injury, fetal alcohol syndrome, alcohol-related birth defects or other undefined disabilities.

Learning Disability

A *learning disability affects the way people with average or above average intelligence take in, process or express information.* Learning disabilities are permanent, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social skills, emotional maturity and coordination.

Part A: An Introduction to Your Program/Service

1. In two or three words, please describe the type of program/service you deliver.

_____

_____

Please describe one program/service only. Possible descriptions could be physical health; social or mental health; housing; educational or training; legal; protection; financial; and recreation. The program/service described is the basis for much of this Questionnaire. A separate Community Service Provider Questionnaire must be completed for each distinct program or service you provide.

2. Your Job Title: _____

_____

More than one title may be included if co-workers providing the program/service have different job titles.

3. Name of Your Organization: _____

4. Name of this Community: _____

Part B: Number & Characteristics of People With Disabilities

5a. In a typical month, how many people are served by the program/service named in Q1? *Give the total number of individuals who usually use your program/service each month. Include people of all ages and people with and without disabilities.*

5b. In the past year, how many people did your program/service serve? *Give the total number of individuals.*

5c. Are the numbers provided in Q5a and 5b, the actual ☐ or estimated number of people served ☐? *Check (✓) one only.*

5d. In the past year, how many people served by your program/service have a disability? *Give the total number of individuals served over the past year. Include people of all ages who show signs of having a disability. Please refer to the disability definitions on page 3.*

5e. Is the number in Q5d an estimate ☐ or the actual number of people with disabilities served ☐? *Check (✓) one only.*

6. **How many of the people with disabilities who were served by your program/ service in the past year were:**
   a. **younger than 15 years of age?** ☐
   b. **15 to 19 years of age?** ☐
   c. **20 to 64 years of age?** ☐
   d. **65 years of age and older?** ☐

7a. **How many of the people with disabilities who were served in the past year are limited in their daily living activities due to difficulties in one of the following areas?** *Please count only those people who show signs of having a single disability in each area of difficulty. Do not include people whose single disability is psychiatric. Please refer to the disability definitions on page 3.*

7b. **How many of the people served in the past year are limited in their daily living activities due to difficulties in more than one of the following areas?** *Some people may be counted in more than one category. For example, an individual might show signs of having a visual impairment as well as a problem processing information. This person would be counted once as having a sensory difficulty and counted again as having a learning difficulty.*

AREA OF DIFFICULTY	Q7a. Number of People Limited in Their Daily Living Activities Due to a Difficulty in One Area Only	Q7b. Number of People Limited in Their Daily Living Activities Due to a Difficulty in More than One Area
Physical (eg. mobility, agility, strength, flexibility or coordination)		
Sensory (eg. seeing, hearing, speaking, or maintaining balance)		
Cognitive (eg. problem not present at birth related to processing information)		
Intellectual (eg. problem at birth affecting rate of development)		
Learning (eg. taking in, processing and expressing information)		
Psychiatric/Mental Health (eg. mental illnesses)	[redacted]	

Part C: DIRECT Services to People with Disabilities

LOCATE THE TYPE OF PROGRAM/SERVICE YOU PROVIDE (as identified in Q1). ANSWER THE FOLLOWING FOUR (4) QUESTIONS FOR THIS PROGRAM/ SERVICE ONLY. *Please note that*:

Q8 refers only to the number of people who use your program/service and show signs of having a disability.

Q9 refers to unpaid caregivers of people with disabilities such as parents and other family members who use your program/service.

Q10 refers to the number of staff and the skills available to deliver the program/service.

Q11 asks you to draw on your professional knowledge to identify new or additional programs/services needed by people with disabilities in the future.

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
			Yes	No	Yes	No
A. Medical/Physical Health Services						
-testing/diagnosis/assessment	..... ☐	..... ☐	☐	☐	☐	☐
-referral	..... ☐	..... ☐	☐	☐	☐	☐
-general medical care/treatment	..... ☐	..... ☐	☐	☐	☐	☐
-occupational therapy or physiotherapy	..... ☐	..... ☐	☐	☐	☐	☐
-audiology or ophthalmology	..... ☐	..... ☐	☐	☐	☐	☐
-speech/language pathology/development	..... ☐	..... ☐	☐	☐	☐	☐
-home/personal care	..... ☐	..... ☐	☐	☐	☐	☐
-health counselling/promotion	..... ☐	..... ☐	☐	☐	☐	☐
-alternative therapy/treatment	..... ☐	..... ☐	☐	☐	☐	☐
-other_____	..... ☐	..... ☐	☐	☐	☐	☐
B. Social& Mental Health Services						
-personal supports	..... ☐	..... ☐	☐	☐	☐	☐
-special intervention/program	..... ☐	..... ☐	☐	☐	☐	☐
-special equipment, aids, tools	..... ☐	..... ☐	☐	☐	☐	☐
-personal or family counselling	..... ☐	..... ☐	☐	☐	☐	☐
-addictions counselling or treatment	..... ☐	..... ☐	☐	☐	☐	☐
-psychological or psychiatric help	..... ☐	..... ☐	☐	☐	☐	☐
-diagnosis or assessment	..... ☐	..... ☐	☐	☐	☐	☐
-referral or information	..... ☐	..... ☐	☐	☐	☐	☐
-parenting support	..... ☐	..... ☐	☐	☐	☐	☐
-alternative therapy/treatment	..... ☐	..... ☐	☐	☐	☐	☐
-other _____	..... ☐	..... ☐	☐	☐	☐	☐

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
			Yes	No	Yes	No
C. Accommodation/Housing Services						
-housing referral or information	..... ☐	..... ☐	☐	☐	☐	☐
-assistance fixing/modifying home	..... ☐	..... ☐	☐	☐	☐	☐
-accommodation/housing subsidy/money	..... ☐	..... ☐	☐	☐	☐	☐
-special accommodation/group home	..... ☐	..... ☐	☐	☐	☐	☐
-other_____	..... ☐	..... ☐	☐	☐	☐	☐
-other_____	..... ☐	..... ☐	☐	☐	☐	☐
D. Education and Training for Children and Youth						
-school readiness/other early intervention	..... ☐	..... ☐	☐	☐	☐	☐
-individualized education plan (IEP)	..... ☐	..... ☐	☐	☐	☐	☐
-special speech or language services	..... ☐	..... ☐	☐	☐	☐	☐
-personal or special needs assistance	..... ☐	..... ☐	☐	☐	☐	☐
-personal counselling	..... ☐	..... ☐	☐	☐	☐	☐
-special equipment, aids, tools	..... ☐	..... ☐	☐	☐	☐	☐
-other _____	..... ☐	..... ☐	☐	☐	☐	☐
-other_____	..... ☐	..... ☐	☐	☐	☐	☐
E. for Adults						
-vocational skill development	..... ☐	..... ☐	☐	☐	☐	☐
-job training	..... ☐	..... ☐	☐	☐	☐	☐
-education program/academic upgrading	..... ☐	..... ☐	☐	☐	☐	☐
-individualized education/training services	..... ☐	..... ☐	☐	☐	☐	☐
-special speech or language services	..... ☐	..... ☐	☐	☐	☐	☐
-personal or special needs assistance	..... ☐	..... ☐	☐	☐	☐	☐
-personal or family counselling	..... ☐	..... ☐	☐	☐	☐	☐
-special equipment, aids, tools	..... ☐	..... ☐	☐	☐	☐	☐
-other _____	..... ☐	..... ☐	☐	☐	☐	☐
-other _____	..... ☐	..... ☐	☐	☐	☐	☐
F. Life Skills, Employment and Residential Supports						
-paid residential support	..... ☐	..... ☐	☐	☐	☐	☐
-life skills training	..... ☐	..... ☐	☐	☐	☐	☐
-in-home support and assistance	..... ☐	..... ☐	☐	☐	☐	☐
-general personal/family/emotional help	..... ☐	..... ☐	☐	☐	☐	☐
-employment/job coaching	..... ☐	..... ☐	☐	☐	☐	☐
-special equipment, aids, tools	..... ☐	..... ☐	☐	☐	☐	☐
-other _____	..... ☐	..... ☐	☐	☐	☐	☐

Type of Program/Service	Q8. How many people with a disability(ies) use this program/ service?	Q9. How many families/ caregivers of people with disabilities use this program/ service?	Q10. Does this program/service have enough staff to serve the people with disabilities and/or their families who WANT OR NEED these services?		Q11. Will additional or new types of programs/ services be needed in 5 to 10 years to serve this community's population with some level of disability?	
			Yes	No	Yes	No
G. Financial Assistance						
-income support/subsidy/basic needs	☐	☐	☐	☐	☐	☐
-budgeting/money management help	☐	☐	☐	☐	☐	☐
-financial information or advice	☐	☐	☐	☐	☐	☐
-other_____	☐	☐	☐	☐	☐	☐
H. Legal Services						
-probation supervision	☐	☐	☐	☐	☐	☐
-placement services	☐	☐	☐	☐	☐	☐
-community justice/local supports	☐	☐	☐	☐	☐	☐
-legal aid	☐	☐	☐	☐	☐	☐
-mediation, negotiation or advocacy	☐	☐	☐	☐	☐	☐
-other _____	☐	☐	☐	☐	☐	☐
I. Protection Services						
-emergency care or shelter	☐	☐	☐	☐	☐	☐
-placement services	☐	☐	☐	☐	☐	☐
-victims' services	☐	☐	☐	☐	☐	☐
-mediation, negotiation or advocacy	☐	☐	☐	☐	☐	☐
-other _____	☐	☐	☐	☐	☐	☐
J. Other Programs and Services						
-disability awareness/education	☐	☐	☐	☐	☐	☐
-respite for caregivers	☐	☐	☐	☐	☐	☐
-emotional/physical help for caregivers	☐	☐	☐	☐	☐	☐
-mobility supports	☐	☐	☐	☐	☐	☐
-transportation services	☐	☐	☐	☐	☐	☐
-special parking program	☐	☐	☐	☐	☐	☐
-equipment/technical aids/tools	☐	☐	☐	☐	☐	☐
-advocacy to get services	☐	☐	☐	☐	☐	☐
-general information/referrals/support	☐	☐	☐	☐	☐	☐
-recreation/social activities	☐	☐	☐	☐	☐	☐
-translation and/or interpretation	☐	☐	☐	☐	☐	☐
-guardianship/trusteeship/supported decision making	☐	☐	☐	☐	☐	☐
-other_____	☐	☐	☐	☐	☐	☐
-other_____	☐	☐	☐	☐	☐	☐

12. To use the program/service described in Q1, people with disabilities or their families/ caregivers pay: *Check (✓) one only.*

- ❒ nothing
- ❒ a small amount
- ❒ Other (explain)_____
- ❒ based on income (eg. income test)
- ❒ the full cost of the service

13a. Do you consider your program/service to be culturally relevant to the people you serve who have a disability? ☐ **Yes** ☐ **No** *Check (✓) one only.*

13b. In a few words, please list the main barriers that you face to providing a culturally relevant program/service._____

_____

_____

_____

14. What are the three main challenges that you face when delivering programs/services to people with a disability(ies)? *Please check (✓) three only.*

- ❒ inadequately trained staff
- ❒ inadequate numbers of staff
- ❒ inflexible funding arrangements
- ❒ no support from leaders
- ❒ lack of inter-agency support
- ❒ lack of political will
- ❒ lack of information
- ❒ client confidentiality issues
- ❒ lack of inter-agency communication
- ❒ physical access to existing facilities/programs
- ❒ inadequate financial resources
- ❒ little/no training available
- ❒ no/poor facilities
- ❒ negative community attitudes
- ❒ lack of community programs/services
- ❒ lack of community support
- ❒ too much paperwork
- ❒ inadequate/poor standards/policies
- ❒ other (explain) _____

15. How is information about disability issues and needs shared among Community Service Providers in your community? *Check (✓) all that apply.*

- ❒ regular case management meetings
- ❒ regular inter-agency meetings
- ❒ informal meetings with other Community Service Providers
- ❒ information is not regularly shared
- ❒ other (explain) _____

16. Based on your front-line experience serving people with disabilities, what do you think are the three main challenges faced by people with disabilities? *Please check (✓) no more than three.*

- ❒ meeting day-to-day shelter/food/clothing needs
- ❒ lack of programs/services
- ❒ finding out about services/programs
- ❒ getting a professional diagnosis/assessment
- ❒ finding out about basic rights
- ❒ feeling safe and secure
- ❒ getting a referral
- ❒ loneliness and isolation
- ❒ getting programs/services from qualified people
- ❒ getting physical access to programs/services/facilities
- ❒ getting help with daily living needs
- ❒ having enough money
- ❒ finding a job
- ❒ dealing with community attitudes
- ❒ paying for programs/services
- ❒ getting support from family members
- ❒ getting follow-up from service providers
- ❒ being understood and accepted
- ❒ other (explain)_____

17. In a few words, please describe good examples of programs/services that have assisted people with disabilities. _____

_____

_____

_____

_____

Part D: Future Program/Service Needs of People with Disabilities

18a. In the next five years, do you think your community will have more ❒; less ❒; or the same number of ❒ people with some type of disability? *Check (✓) one only.*

18b. How many more or less? *Check (✓) one only.*

- ❒ 1% - 5% decrease
- ❒ 6%-10% decrease
- ❒ 11%-15% decrease
- ❒ 1%-5% increase
- ❒ 6%-10% increase
- ❒ 11%-15% increase
- ❒ no change
- ❒ don't know
- ❒ other (*explain*)_____

18c. What are the <u>two main factors</u> leading you to expect increases OR decreases in the incidence of disability in your community?

If you said 'increase'.... *(Check (✓) only <u>two</u>.)*	**If you said 'decrease'.....** *(Check (✓) only <u>two</u>.)*
❒ inadequate medical care	❒ better medical care
❒ lack of pre-natal/post-natal education	❒ more pre-natal/post-natal education
❒ high use of alcohol, drugs and/or solvents	❒ less use of alcohol, drugs and/or solvents
❒ high use of tobacco	❒ less use of tobacco
❒ high rate of accidents/injuries	❒ efforts to prevent accidents/injuries
❒ high rate of work-related accidents/injuries	❒ efforts to prevent work-related accidents/injuries
❒ poverty	❒ less poverty
❒ abuse and/or neglect	❒ less abuse and/or neglect
❒ family genetics	❒ genetic screening
❒ aging population	❒ more acknowledgement of FAS/FAE
❒ better/more diagnosis or assessment	❒ better/more diagnosis or assessment
❒ other (explain) _____	❒ other (explain) _____
❒ other (explain) _____	❒ other (explain) _____

19. What did we forget to ask you about your work with people with disability(ies)?

_____

_____

_____

_____

_____

Please complete the Community Service Provider Questionnaire within one (1) month of receiving it. All completed questionnaires should be returned to Lutra Associates Ltd., Box 1866, Yellowknife, NT XIA 2P4

Please attach any working papers that you may have used to complete this questionnaire, ensuring that no individuals can be identified. THANK YOU.

Information and Confidentiality Form

for People Completing the Personal Questionnaire
Needs Assessment of Persons with Disabilities in the Western NWT

I have been given a Personal Questionnaire by a Service Provider. I understand the objectives of the **Needs Assessment of Persons with Disabilities** in the NWT. I understand that the information that I provide in the Questionnaire will be kept confidential and that no one will know what I said or be able to identify me as a result of my participation in this Needs Assessment. I understand that the Service Provider who gave me the Personal Questionnaire will collect the completed Questionnaire and will keep all the information confidential and not attach my name to the Questionnaire.

I understand that the person helping me to complete the Personal Questionnaire will also sign this form. This will ensure that this person respects my privacy and keeps my information confidential.

I understand that:

- I have the right to refuse to participate in this Needs Assessment, and that
- the report that is produced from this Assessment will belong to the Yellowknife Association for Community Living, NWT Council for Disabled Persons, Department of Health and Social Services, Department of Education, Culture and Employment, the Metis Nation of the NWT, and the YWCA of Yellowknife.

If I have any questions or concerns about this Needs Assessment, I can contact:

Aggie Brockman,
Executive Director,
NWT Council for Disabled Persons,
Yellowknife, NT XIA 2P1
Phone: (867) 873-8230

_____ _____

Signature Date

_____ _____

Signature of Person Helping to Complete the Personal Questionnaire Date

A Needs Assessment of Persons with Disabilities in the NWT - PERSONAL QUESTIONNAIRE

Have you read the August News Bulletin describing this Needs Assessment?

A disability is *any degree of physical, sensory, cognitive, intellectual, learning or psychiatric limitation which causes difficulty in the usual activities of daily living*. A disability may have been diagnosed/assessed, named by a professional or be known only to yourself. **If you have a disability, please complete the Personal Questionnaire**.

There are many kinds of disabilities. They are defined as:

A Physical Disability *involves a significant loss of mobility, agility, strength, flexibility or coordination*. Some conditions which involve physical disabilities are paraplegia, quadriplegia, amputation, cerebral palsy, polio, multiple sclerosis and arthritis.

A Sensory Disability *involves the senses*. Sensory disabilities include: blindness or significant vision loss, deafness or significant hearing loss, the inability to speak, and a lack of balance from disorders such as Vertigo or Meniere's Disease.

A Cognitive Disability *is usually a degenerative condition that affects the brain's ability to process information*. It is <u>not</u> present from birth. Cognitive disabilities may include Alzheimer's, senility and late stage alcoholism.

An Intellectual Disability *affects the rate at which a person develops, learns and/or remembers*. This disability is <u>usually</u> present from birth. People with intellectual disabilities may have Down's Syndrome, traumatic brain injury, fetal alcohol syndrome, alcohol-related birth defects or other undefined disabilities.

A Learning Disability *affects the way people with average or above average intelligence take in, process or express information*. Learning disabilities are permanent, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social skills, emotional maturity and coordination.

Please do <u>not</u> complete a Personal Questionnaire if you have a psychiatric disability/illness and no other type of disability.

You will receive this Questionnaire from a front-line worker who knows about disabilities. We call this person a Community Service Provider. The Community Service Provider can help you to complete this Questionnaire. You can also ask for help from another adult in the community who you know and trust. In all cases, an adult family member or another adult in the community should complete the Personal Questionnaire on behalf of people who are younger than 15 years of age.

Before filling in the Personal Questionnaire, please read over the **Information and Confidentiality Form** (or ask the Community Service Provider to read the form to you). As stated in the Information and Confidentiality Form, no one will know what you said or be able to identify you from the information you give. You are asked to sign the form to show that you understand this. Anyone helping you with the Personal Questionnaire must also sign the form. By signing the form, they promise not to share any of the information about you.

Please complete only one Personal Questionnaire. It should take 20 to 40 minutes. Please complete and return this Questionnaire and the Information and Confidentiality Form within 4 weeks of receiving them.

When you have completed the Personal Questionnaire, please return it along with the signed Information and Confidentiality Form, to the Community Service Provider who first gave the Questionnaire to you. Please do not staple the signed Information and Confidentiality Form to the Personal Questionnaire.

If you would prefer to receive the Personal Questionnaire in an alternative format (eg. orally) or if you are uncertain about providing information or answering the questions, you can talk to the Community Service Provider. Or you can contact Sandy Auchterlonie, Lois Little or Bob Stephen at Lutra Associates. Call Sandy, Lois or Bob collect at (867) 873-8903 or (867) 920-2177 or send a fax to (867) 873-8368 or send an e-mail at xlutra@ssimicro.com

Part A: Introducing Yourself

1. I live in the community of: _____

2. I was born in the community of: _____

3. I consider my home to be: *Check (✓) one only.*

- **a. in this community or region** ☐
- **b. in another NWT region** ☐
- **c. in a region of Nunavut** ☐
- **d. outside of the NWT and Nunavut** ☐

4. I am: ❒ Male ❒ Female

5. I was born in: 19____

6. My ancestry is : ❒ Dene ❒ Metis ❒ Inuvialuit ❒ Inuit ❒ Non-Aboriginal

7. The language I understand the best is:

❒ English	❒ French	❒ Inuvialuktun	❒ Inuktitut
❒ Gwich'in	❒ Slavey	❒ Dogrib	❒ Chipewyan
❒ Cree	❒ Other (explain) _____		

8. Right now, I live:

- ❒ alone
- ❒ with my mother and/or father
- ❒ with my spouse and/or my children
- ❒ with my grandparent(s)
- ❒ with other family member(s)
- ❒ in a seniors' or a group home
- ❒ with foster parents/legal guardian
- ❒ with other non-family members in a private residence
- ❒ in an institution (eg. jail, detention facility, treatment centre, supervised care)
- ❒ other (explain) _____

The next questions ask about physical, hearing, speech, visual, cognitive, intellectual, learning and psychiatric disabilities (in that order). You do not have to answer all of the questions. Answer questions only for the disability that you have.

Part B: About Your Disability(ies)

PHYSICAL DISABILITIES

A physical disability involves a significant loss of mobility, agility, strength, flexibility or coordination. Some conditions which involve physical disabilities are paraplegia, quadriplegia, amputation, cerebral palsy, polio, multiple sclerosis and arthritis.

9. Do you have a physical disability(ies)? ❒ Yes ❒ No

If you answered no, go to Q15a. If yes, please continue.

10a. Has this disability(ies) been diagnosed/assessed or named by a professional?

❒ Yes ❒ No

10b. Would you describe your physical disability(ies) as: *Please check (✓) one only.*

❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

11. Do you expect that your physical disability(ies) will get worse in the future?

❒ Yes ❒ No ❒ Don't know

12. What is the main reason for your physical disability(ies)? *Check (✓) one only.*

❒ born with it
❒ accident
❒ injured while working
❒ other family members have the same condition
❒ was neglected
❒ violence and/or abuse
❒ due to my age
❒ pre-natal exposure to alcohol/drugs
❒ illness or a disease
❒ my own use of alcohol/drugs/solvents
❒ don't know
❒ other *(explain)*_____

13a. Do you use any special aids/equipment/support to help you to cope with your physical disability(ies)? ❒ Yes ❒ No *If no, go to Q13c. If yes, please continue.*

13b. What special aids/equipment/support do you use now? *Check (✓) all that apply*

13c. What special aids/equipment/support do you need now but do not have?
Check (✓) all that apply.

Special Aids, Equipment or Support	Q13b. Aids/Equipment/ Support Used Now	Q13c. Aids/Equipment/ Support I Need Now But Do Not Have
- back or leg brace	❒	❒
- prosthesis	❒	❒
- cane/crutches/walker	❒	❒
- scooter	❒	❒
- wheelchair/sports wheelchair	❒	❒
- voice activated controls	❒	❒
- positioning devices	❒	❒
- special transportation (eg. bus/van)	❒	❒
- adaptations/changes to regular motor vehicles	❒	❒
- adaptations/changes in the home	❒	❒
- adaptations/changes to the work place/ school	❒	❒
- adaptations/changes to other community buildings	❒	❒
- special computer equipment/software	❒	❒
- other (explain)_____	❒	❒
- other (explain)_____	❒	❒

14. Please indicate which of the following daily living activities are <u>difficult</u> for you:

a. with the use of special equipment/aids/support. *Check (✓) all that apply.*

b. without the use of special equipment/aids/support. *Check (✓) all that apply.*

Daily Living Activities	Q14a. Difficult WITH the Use of Special Aids/ Equipment/Support	Q14b. Difficult WITHOUT the Use of Special Aids/ Equipment/Support
- feeding,dressing and/or caring for myself	❒	❒
- lifting, carrying and/or moving things	❒	❒
- standing for long periods	❒	❒
- walking	❒	❒
- getting in/out of bed	❒	❒
- bending down	❒	❒
- reaching, grasping or handling things	❒	❒
- picking things up	❒	❒
- working or participating at school	❒	❒
- getting or keeping a job	❒	❒
- participating in social/recreation activities	❒	❒
- playing sports or keeping physically fit	❒	❒
- other (explain)_____	❒	❒

HEARING DISABILITIES

A hearing disability is a sensory disability. These disabilities involve the senses (eg. seeing, hearing, speaking and balance). Hearing disabilities include deafness, a significant hearing loss and ear related problems such as Vertigo or Meniere's Disease.

15a. Do you have a hearing impairment? ❒ Yes ❒ No

15b. Are you deaf? ❒ Yes ❒ No

15c. Are you limited in other ways as a result of an ear-related problem?

❒ Yes ❒ No

*If you answered **no** to each of Q15a, Q15b **AND** Q15c, go to Q22a. If yes to either of Q15a, Q15b **OR** Q15c, please continue.*

16a. Do you use sign language? ❒ Yes ❒ No

16b. Do you speech read or lip read? ❒ Yes ❒ No

17a. Has this disability(ies) been diagnosed/assessed or named by a professional?

❒ Yes ❒ No

17b. Would you describe your hearing disability(ies) as: *Please check (✓) one only.*

❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

18. Do you expect that your hearing disability will get worse in the future?

❒ Yes ❒ No ❒ Don't know

19. What is the main reason for your hearing disability(ies)? *Check (✓) one only.*

❒ born with it
❒ an accident
❒ injured while working
❒ due to my age
❒ was abused and/or neglected
❒ illness or a disease
❒ due to my own use of alcohol/drugs/solvents
❒ don't know
❒ other family members have same condition
❒ other (explain) _____

20a. Do you use any special aids/equipment/support to help you to cope with your hearing disability? ❒Yes ❒ No *If no, go to Q20c. If yes, please continue.*

20b. What special aids/equipment/support do you use now? *Check (✓) all that apply.*
20c. What special aids/equipment/support do you need now but do not have?

Special Aids, Equipment or Support	Q20b. Aids/Equipment/ Support Used Now	Q20c. Aids/Equipment/ Support I Need Now But Do Not Have
- hearing aid	❐	❐
- caption decoder	❐	❐
- amplification/FM system	❐	❐
- special computer equipment/software	❐	❐
- oral interpreter/sign language interpreter/translator	❐	❐
- other translation/interpretation equipment/aids	❐	❐
- flashing or visual alarms	❐	❐
- volume control telephone	❐	❐
- adaptations/changes to the home	❐	❐
- adaptations/changes to the work place or school	❐	❐
- adaptations/changes to other community buildings	❐	❐
- other (explain) _____	❐	❐

21. Please indicate which of the following daily living activities are difficult for you:

a. with the use of special equipment/aids/support. *Check (✓) all that apply.*

b. without the use of special equipment/aids/support. *Check (✓) all that apply.*

Daily Living Activities	Q21a. Difficult WITH the Use of Special Aids/ Equipment/ Support	Q21b. Difficult WITHOUT the Use of Special Aids/ Equipment/Support
- communicating with others	❐	❐
- hearing what is being said	❐	❐
- understanding other people	❐	❐
- maintaining balance or posture	❐	❐
- hand/eye or physical coordination	❐	❐
- getting or keeping a job	❐	❐
- participating at work or school	❐	❐
- playing sports or keeping physically fit	❐	❐
- participating in social/recreation activities	❐	❐
- other (explain) _____	❐	❐

SPEECH DISABILITIES

A speech disability is a sensory disability. These disabilities involve the senses (eg. seeing, hearing, speaking and balance). Speech disabilities include the inability to speak, a speech impairment, difficulty speaking and a significant loss of speech.

22a. Do you have a speech impairment or difficulty speaking? ❒ Yes ❒ No

22b. Are you unable to speak? ❒ Yes ❒ No

*If you answered no to **BOTH** Q22a and 22b, go to Q28a. If yes to Q22a **OR** Q22b, please continue.*

23a. Has this disability(ies) been diagnosed/assessed or named by a professional?
❒ Yes ❒ No

23b. Would you describe your speech disability(ies) as: *Please check (✓) one only.*
❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

24. Do you expect that your speech disability will get worse in the future?
❒ Yes ❒ No ❒ Don't know

25. What is the main reason for your speech disability(ies)? *Check (✓) one only.*

❒ born with it
❒ injured while working
❒ other family members have same condition
❒ was abused and/or neglected
❒ due to my own use of alcohol/drugs/solvents
❒ accident
❒ due to my age
❒ illness or a disease
❒ don't know
❒other (explain) _____

26a. Do you use any special aids/equipment/support to help you to cope with this disability? ❒ Yes ❒ No *If no, go to Q26c. If yes, please continue.*

26b. What special aids/equipment/support do you use now? *Check (✓) all that apply.*

26c. What special aids/equipment/support do you need now but do not have?

Check (✓) all that apply.

Special Aids, Equipment or Support	Q26b. Aids/Equipment /Support Used Now	Q26c. Aids/Equipment/ Support I Need Now But Do Not Have
-communication board	❒	❒
-special computer equipment/software	❒	❒
-speech viewer	❒	❒
-adaptations/changes to the home	❒	❒
-adaptations/changes to the work place or school	❒	❒
-adaptations/changes to other community buildings	❒	❒
-other (explain) _____	❒	❒
-other (explain) _____	❒	❒

27. Please indicate which of the following daily living activities are difficult for you:

a. with the use of special equipment/aids/support. *Check (✓) all that apply.*

b. without the use of special equipment/aids/support. *Check (✓) all that apply.*

Daily Living Activities	Q27a. Difficult WITH the Use of Special Aids/ Equipment/Support	Q27b. Difficult WITHOUT the Use of Special Aids/ Equipment/Support
- making others understand	❒	❒
- getting or keeping a job	❒	❒
- participating at work or at school	❒	❒
- playing sports or keeping physically fit	❒	❒
- participating in social/recreation activities	❒	❒
- other (explain) _____	❒	❒
- other (explain) _____	❒	❒

VISUAL DISABILITIES

A visual disability is a sensory disability. These disabilities involve the senses (eg. seeing, hearing, speaking and balance). Visual disabilities include blindness or significant loss of vision.

28a. Do you have a visual impairment or difficulty seeing? ❒ Yes ❒ No

28b. Are you blind? ❒ Yes ❒ No

*If you answered no to **BOTH** Q28a and Q28b, go to Q34. If yes to Q28a **OR** Q28b, please continue.*

29a. Has this visual disability(ies) been <u>diagnosed/assessed</u>? ❒ Yes ❒ No

29b. Would you describe your visual disability(ies) as: *Please check (✓) <u>one</u> only.*

❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

30. Do you expect that your visual disability will get worse in the future?

❒ Yes ❒ No ❒ Don't know

31. What is the <u>main</u> reason for your visual disability(ies)? *Check (✓) <u>one</u> only.*

❒ born with it
❒ injured while working
❒ other family members have same condition
❒ was abused and/or neglected
❒ due to my use of alcohol/drugs/solvents
❒ accident
❒ due to my age
❒ illness or a disease
❒ don't know
❒ other (explain) _____

32a. Do you use any special aids/equipment to help you to cope with your visual disability? ❒ Yes ❒ No *If no, go to Q32c. If yes, continue*

32b. What special aids/equipment/support do you use now? *Check (√) all that apply.*
32c. What special aids/equipment/support do you need now but do not have?

Special Aids, Equipment or Support	Q32b. Aids/Equipment/ Support Used Now	Q32c. Aids/Equipment/ Support I Need Now But Do Not Have
-large print reading materials	❒	❒
-large computer monitors	❒	❒
-specialized computer software	❒	❒
-magnification devices	❒	❒
-braille reading materials	❒	❒
-braille typewriter/computer/software	❒	❒
-audio tapes (eg. 'talking books')	❒	❒
-mobility supports (eg.cane, seeing eye dog)	❒	❒
-adaptations/changes to the home	❒	❒
-adaptations/changes to the work place or school	❒	❒
-adaptations/changes to other community buildings	❒	❒
-other (explain)_____	❒	❒

33. Please indicate which of the following daily living activities are difficult for you:

a. with the use of special equipment/aids/supports. *Check (√) all that apply.*

b. without the use of special equipment/aids/supports. *Check (√) all that apply.*

Daily Living Activities	Q33a. Difficult WITH the Use of Special Aids/ Equipment/Support	Q33b. Difficult WITHOUT the Use of Special Aids/ Equipment/Support
- feeding, dressing and/or caring for myself	❒	❒
- moving around	❒	❒
- reading	❒	❒
- writing	❒	❒
- getting or keeping a job	❒	❒
- understanding things around me	❒	❒
- participating at work or school	❒	❒
- playing sports or keeping physically fit	❒	❒
- participating in social/recreation activities	❒	❒
- other (explain)_____	❒	❒

COGNITIVE DISABILITIES

A cognitive disability is usually a degenerative condition that affects the brain's ability to process information. It is not present from birth. Cognitive disabilities may include Alzheimer's, senility and late stage alcoholism.

34. Do you have a worsening condition that hinders your ability to process information (sometimes called a cognitive disability)? ❒ Yes ❒ No
If you answered no, go to Q39. If yes , please continue.

35a. Has this disability(ies) been diagnosed/assessed or named by a professional?
❒ Yes ❒ No

35b. Would you describe your cognitive disability(ies) as: *Please check (✓) one only.*
❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

36. What is the main reason for your cognitive disability(ies)? *Check (✓) one only.*

❒ illness or a disease
❒ injured while working
❒ other family members have same condition
❒ was abused and/or neglected
❒ due to my use of alcohol/drugs/solvents
❒ other (explain) _____
❒ accident
❒ due to my age
❒ don't know

37a. Do you use any special aids/equipment to help you to cope with this disability?
❒ Yes ❒ No *If no, go to Q37c. If yes, please continue.*

37b. What special aids/equipment/support do you use now?

37c. What special aids/equipment/support do you need now but do not have?

Check (✓) all that apply.

Special Aids, Equipment or Support	Q37b. Aids/Equipment/ Support Used Now	Q37c. Aids/Equipment/ Support I Need Now But Do Not Have
-special equipment to help you move around	❐	❐
-special equipment to manage information	❐	❐
-special computer equipment/software	❐	❐
-adaptations/changes to the home	❐	❐
-adaptations/changes to the work place or school	❐	❐
-adaptations/changes to other community buildings	❐	❐
-other (explain) _____	❐	❐

38. Please indicate which of the following daily living activities are difficult for you:

a. with the use of special equipment/aids/support. *Check (✓) all that apply.*

b. without the use of special equipment/aids/support. *Check (✓) all that apply.*

Daily Living Activities	Q38a. Difficult WITH the Use of Special Aids/ Equipment/Support	Q38b. Difficult WITHOUT the Use of Special Aids/ Equipment/Support
- feeding, dressing and/or caring for myself	❐	❐
- moving around	❐	❐
- reading and/or writing	❐	❐
- getting or keeping a job	❐	❐
- being understood by others around me	❐	❐
- understanding things around me	❐	❐
- participating at work or school	❐	❐
- playing sports or keeping physically fit	❐	❐
- participating in social/recreation activities	❐	❐
- other (explain)_____	❐	❐
- other (explain) _____	❐	❐

INTELLECTUAL DISABILITIES

An intellectual disability affects the rate at which a person develops, learns and/or remembers. This disability is usually present from birth. People with intellectual disabilities may have Down's Syndrome, traumatic brain injury, fetal alcohol syndrome, alcohol-related birth defects or other undefined disabilities.

39. Are you limited by the rate at which you develop, learn and/or remember (sometimes called an intellectual disability)? ❒ Yes ❒ No
If you answered no, go to Q44. If yes, please continue.

40a. Has this disability(ies) been diagnosed/assessed or named by a professional?
❒ Yes ❒ No

40b. Would you describe your intellectual disability(ies) as: *Check (✓) one only.*
❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

41. What is the main reason for your intellectual disability(ies)? *Check (✓) one only.*

❒ illness or a disease
❒ accident
❒ injured while working
❒ due to my age
❒ other family members have same condition
❒ don't know
❒ was abused and/or neglected
❒ due to my use of alcohol/drugs/solvents
❒ born with it/birth trauma/pre-natal problems
❒ other (explain) _____

42a. Do you use any special aids/equipment/support to help you to cope with your intellectual disability? ❒ Yes ❒ No *If no, go to Q42c. If yes, please continue.*

42b. What special aids/equipment/support do you use now?
42c. What special aids/equipment/support do you need now but do not have?

Special Aids, Equipment or Support	Q42b. Aids/Equipment/ Support Used Now	Q42c. Aids/Equipment/ Support I Need Now But Do Not Have/Get
-special equipment to help in learning	❒	❒
-special aids to help organize information	❒	❒
-special computer equipment or software	❒	❒
-adaptations/changes to the home	❒	❒
-adaptations/changes in the work place or school	❒	❒
-adaptations/changes to other community buildings	❒	❒
-other (explain)_____	❒	❒
-other (explain) _____		

43. Please indicate which of the following daily living activities are difficult for you:

a. with the use of special equipment/aids/support. *Check (✓) all that apply.*

b. without the use of special equipment/aids/support. *Check (✓) all that apply.*

Daily Living Activities	Q43a. Difficult WITH the Use of Special Aids/Equipment/ Support	Q43b. Difficult WITHOUT the Use of Special Aids/ Equipment/Support
- caring for myself and/or my home	❒	❒
- managing my money	❒	❒
- moving around	❒	❒
- reading and/or writing	❒	❒
- getting or keeping a job	❒	❒
- being understood by others around me	❒	❒
- understanding things around me	❒	❒
- participating at work or school	❒	❒
- playing sports or keeping physically fit	❒	❒
- participating in social/recreation activities	❒	❒
- other (explain)_____	❒	❒

LEARNING DISABILITIES

A learning disability affects the way people with average or above average intelligence take in, process or express information. Learning disabilities are permanent, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social skills, emotional maturity and coordination.

44. Do you have problems with memory, attention, reading, writing, arithmetic, reasoning and/or social skills (sometimes called a learning disability)?

❒ Yes ❒ No *If no, go to Q48. If yes, please continue.*

45a. Has this disability(ies) been diagnosed/assessed or named by a professional?

❒ Yes ❒ No

45b. Would you describe your learning disability(ies) as: *Please check (✓) one only.*

❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

46. What is the main reason for your learning disability(ies)? *Check (✓) one only.*

❒ illness or a disease
❒ injured while working
❒ other family members have same condition
❒ was abused and/or neglected
❒ due to my own use of alcohol/drugs/solvents
❒ other (explain) _____
❒ accident
❒ due to my age
❒ born with it
❒ don't know

47. Please indicate which of the following daily living activities are difficult for you:

a. with the use of special equipment/aids/supports. *Check (✓) all that apply.*

b. without the use of special equipment/aids/supports. *Check (✓) all that apply.*

Daily Living Activities	Q47a. Difficult WITH the Use of Special Aids/ Equipment/ Support	Q47b. Difficult WITHOUT the Use of Special Aids/ Equipment/ Support
- caring for myself and/or home	❒	❒
- managing my money	❒	❒
- moving around	❒	❒
- reading and/or writing	❒	❒
- getting or keeping a job	❒	❒
- being understood by others around me	❒	❒
- understanding things around me	❒	❒
- participating at work or school	❒	❒
- playing sports or keeping physically fit	❒	❒
- participating in social/recreation activities	❒	❒
- other (explain) _____	❒	❒
- other (explain)_____	❒	❒

PSYCHIATRIC DISABILITIES OR MENTAL ILLNESSES

Psychiatric disabilities or illnesses are not included in this Needs Assessment except in the cases where present along with another disability.

ANSWER Q 48 AND 49 a & b ONLY IF YOU HAVE A PSYCHIATRIC DISABILITY AS WELL AS A PHYSICAL, HEARING, SPEECH, VISUAL, COGNITIVE, INTELLECTUAL AND/OR LEARNING DISABILITY.

48. In addition to the disabilities that you have already described, do you also have a psychiatric disability or mental illness? ❒ Yes ❒ No

If no, go to Q50. If yes, please continue.

49a. Has this disability(ies) been diagnosed/assessed or named by a professional?

❒ Yes ❒ No

49b. Would you describe your psychiatric disability(ies) as: *Check (✓) one only.*

❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

Part C: About Your Daily Living Needs

Please read the whole list of programs/services in each group before checking those you use now, those you need now but are currently not getting, and those you may need in the future.

Type of Programs/Services	Q50a. Check (✓) those programs/ services which you USE NOW.	Q50b. Check (✓) those programs/services which you NEED NOW BUT ARE NOT GETTING.	Q50c. Check (✓) those programs/ services which you may NEED IN THE FUTURE.
A. Medical/Physical Health Services			
-testing/diagnosis/assessment	❒	❒	❒
-referral services	❒	❒	❒
-general medical care/treatment	❒	❒	❒
-occupational therapy or physiotherapy	❒	❒	❒
-audiology or ophthalmology	❒	❒	❒
-speech/language pathology/development	❒	❒	❒
-health counselling or promotion	❒	❒	❒
-home/personal care	❒	❒	❒
-alternative therapy/treatment	❒	❒	❒
-other_____	❒	❒	❒

Type of Programs/Services	Q50a. Check (✓) those programs/ services which you USE NOW.	Q50b. Check (✓) those programs/services which you NEED NOW BUT ARE NOT GETTING.	Q50c. Check (✓) those programs/ services which you may NEED IN THE FUTURE.
B. Social and Mental Health Services			
-personal supports.....	❒	❒	❒
-specialized intervention/program.....	❒	❒	❒
-special equipment, aids, tools.....	❒	❒	❒
-personal or family counselling.....	❒	❒	❒
-addictions counselling or treatment	❒	❒	❒
-psychological or psychiatric help.....	❒	❒	❒
-diagnosis or assessment	❒	❒	❒
-referral or information.....	❒	❒	❒
-parenting support.....	❒	❒	❒
-alternative therapy/treatment.....	❒	❒	❒
-other _____	❒	❒	❒
C. Accommodation/Housing Services			
-housing referral or information.....	❒	❒	❒
-help fixing/changing the home.....	❒	❒	❒
-accommodation/housing subsidy/money..	❒	❒	❒
-special accommodation/group home.....	❒	❒	❒
-other _____	❒	❒	❒
D. Education and Training for Children and Youth			
-school readiness/other preschool program.	❒	❒	❒
-individualized education plan (IEP).....	❒	❒	❒
-specialized speech or language services..	❒	❒	❒
-personal or special help in the classroom...	❒	❒	❒
-personal counselling	❒	❒	❒
-special equipment, aids, tools in school ...	❒	❒	❒
-other_____	❒	❒	❒

Type of Programs/Services	Q50a. Check (✓) those programs/ services which you USE NOW.	Q50b. Check (✓) those programs/services which you NEED NOW BUT ARE NOT GETTING.	Q50c. Check (✓) those programs/ services which you may NEED IN THE FUTURE.
E. Education and Training for Adults			
-job skill development	❒	❒	❒
-job training.....	❒	❒	❒
-education program/academic upgrading ..	❒	❒	❒
-individualized education/training services..	❒	❒	❒
-specialized speech or language services..	❒	❒	❒
-personal or special needs assistance.....	❒	❒	❒
-personal or family counselling	❒	❒	❒
-special equipment, aids, tools	❒	❒	❒
-other _____	❒	❒	❒
F. Life Skills, Employment and Residential Supports			
-paid residential support.....	❒	❒	❒
-life skills training.....	❒	❒	❒
-in-home support and assistance.....	❒	❒	❒
-general personal/family/emotional support.	❒	❒	❒
-employment or job coaching.....	❒	❒	❒
-special equipment, aids, tools.....	❒	❒	❒
-other _____	❒	❒	❒
G. Financial Assistance			
-income support/subsidy/basic needs.....	❒	❒	❒
-budgeting/money management help.....	❒	❒	❒
-financial information or advice.....	❒	❒	❒
-other_____	❒	❒	❒
H. Legal Services			
-probation supervision	❒	❒	❒
-placement services	❒	❒	❒
-community justice/local supports.....	❒	❒	❒
-legal aid.....	❒	❒	❒
-mediation, negotiation or advocacy.....	❒	❒	❒
-other_____	❒	❒	❒

Type of Programs/Services	Q50a. Check (✓) those programs/ services which you USE NOW.	Q50b. Check (✓) those programs/services which you NEED NOW BUT ARE NOT GETTING.	Q50c. Check (✓) those programs/ services which you may NEED IN THE FUTURE.
I. Protection Services			
-emergency care or shelter	❒	❒	❒
-placement services	❒	❒	❒
-victims' services	❒	❒	❒
-mediation, negotiation or advocacy.....	❒	❒	❒
-other_____	❒	❒	❒
J. Other Programs and Services			
-disability awareness/education.....	❒	❒	❒
-respite	❒	❒	❒
-mobility supports (eg. seeing eye dog)	❒	❒	❒
-transportation services.....	❒	❒	❒
-special parking program	❒	❒	❒
-equipment/technical aids/tools.....	❒	❒	❒
-advocacy to get services.....	❒	❒	❒
-general information/referrals/support.....	❒	❒	❒
-recreation/social activities.....	❒	❒	❒
-translation and/or interpretation.....	❒	❒	❒
-guardianship/trusteeship/supported decision-making.....	❒	❒	❒
-other_____	❒	❒	❒
-other_____	❒	❒	❒

51a. Do the programs/services you get meet your cultural needs? ❒ Yes ❒ No

51b. In a few words, please describe why you say this? _____

_____

_____

52a. Please describe your day to day activities at work, at home and/or at school.

Check (✓) all that apply. Check (✓) here ❒, if this does not apply to you.

❒ Go to school full or part-time
❒ Go to a supervised day program for adults
❒ Go to supervised day program for children
❒ Sew/do arts/crafts
❒ Have a casual or seasonal job
❒ Babysit
❒ Other _____
❒ Other _____

❒ Go to a full or part-time training program
❒ Have a part-time job (30 hrs. or less a week)
❒ Own and/or operate my own business
❒ Have a full time job (30 hrs. or more a week)
❒ Hunt/trap/fish/spend time on land
❒ Help with the housework
❒ Other _____
❒ Other _____

52b. Please describe your day to day social, recreation and leisure activities .

Check (✓) all that apply. Check (✓) here ❒, if this does not apply to you.

❒ Visit people / spend time with friends
❒ Use the Internet
❒ Go to church
❒ Join physical fitness/sports groups
❒ Volunteer in community
❒ Go to community dances
❒ Go to community feasts
❒ Other _____
❒ Other _____

❒ Watch T.V.
❒ Go shopping
❒ Go to the coffee shop or arcade
❒ Have lots of hobbies
❒ Parenting / look after my family
❒ Go to community meetings
❒ Attend other social events
❒ Other _____
❒ Other _____

53. What are the three main problems that you face in your day-to-day living? *Please check (✓) no more than three.*

❒ getting food, shelter and clothing
❒ getting help with day to day living
❒ finding out about services/programs
❒ getting into services/programs
❒ getting a professional diagnosis or assessment
❒ getting services from trained people
❒ getting the help I need to live on my own
❒ dealing with community attitudes
❒ having to travel outside my community to get help
❒ dealing with the attitudes of professionals

❒ having enough money
❒ feeling safe and secure
❒ getting a referral
❒ finding a job
❒ feeling all alone
❒ finding out about my basic rights
❒ paying for the services I need
❒ getting help from family members
❒ feeling good about myself
❒ feeling accepted in my community

❒ other (explain) _____

_____

If you are younger than 15 years of age (or are completing this questionnaire for someone of this age), please go to Q60.

Part D: To Be Completed by People Who are 15 Years of Age and Older

54. What is your marital status?

❒ single/never married ❒ married/live common-law ❒divorced/separated/widowed

55. How many people depend on you for food/shelter/clothing? *Please circle one.*

None 1 2 3 4 5 6 more than 6

56. What is the highest grade you have completed at school or through upgrading?

Please circle one.

Highest grade completed 13 12 11 10 9 8 7 6 5 4 3 2 1 None

57. What diplomas, certificates, and/or degrees have you received?

Check (√) all that apply.

- ❒ Certificate of High School Achievement
- ❒ High School Diploma
- ❒ College Diploma or Certificate
- ❒ Some University Credits
- ❒ University Degree
- ❒ Other Training Certificates
- ❒ None

58a. Do you currently have a job or run a business? ❒ Yes ❒ No

58b. If no to 58a, do you want a job or to run your own business? ❒ Yes ❒ No

58c. Is there any reason why you could not take a job/run your own business?

❒ Yes ❒ No

58d. If yes to Q58c, what is the reason?

- ❒ disability or illness
- ❒ too old
- ❒ personal or family responsibility
- ❒ other (eg. going to school, vacation)

59a. What was your total personal income last year?

59b. If you lived in a private residence last year, what was the total income for the household? *The information that you provide on income will not affect the services or benefits that you receive.*

Income Range	Q59a. Personal Income	Q59b. Household Income
0 - $9,999	❒	❒
$10,000-$19,999	❒	❒
$20,000-$29,999	❒	❒
$30,000-$39,999	❒	❒
$40,000-$59,999	❒	❒
$60,000 or more	❒	❒

60. What did we forget to ask you about your disability or about living with a disability?

_____

_____

_____

_____

_____

_____

DON'T FORGET TO RETURN YOUR COMPLETED QUESTIONNAIRE AND SIGNED INFORMATION AND CONFIDENTIALITY FORM TO THE COMMUNITY SERVICE PROVIDER WHO GAVE IT TO YOU.

THANK YOU FOR YOUR TIME AND INPUT INTO THIS NEEDS ASSESSMENT.

A Needs Assessment of Persons with Disabilities in the NWT - PARENT/CAREGIVER QUESTIONNAIRE

Have you read the August News Bulletin about this Needs Assessment?

The **Parent/Caregiver Questionnaire** should be completed by individuals who look after a person(s) with a disability(ies), and do not get paid for the care they provide. Parents or Caregivers may look after a person with a disability all of the time, part-time or for only a few hours on a regular or irregular basis.

People who are paid to provide care to a person with a disability should complete the Community Service Provider Questionnaire.

A disability is *any degree of physical, sensory, cognitive, intellectual, learning or psychiatric limitation which causes difficulty in the usual activities of daily living*. For this Needs Assessment, the main types of disabilities are defined as:

A Physical Disability *involves a significant loss of mobility, agility, strength, flexibility or coordination*. Some conditions which involve physical disabilities are paraplegia, quadriplegia, amputation, cerebral palsy, polio, multiple sclerosis and arthritis.

A Sensory Disability *involves the senses*. Sensory disabilities include: blindness or significant vision loss, deafness or significant hearing loss, the inability to speak, and a lack of balance from disorders such as Vertigo or Meniere's Disease.

A Cognitive Disability *is usually a degenerative condition that affects the brain's ability to process information*. It is not present from birth. Cognitive disabilities may include Alzheimer's, senility and late stage alcoholism.

An Intellectual Disability *affects the rate at which a person develops, learns and/or remembers*. This disability is usually present from birth. People with intellectual disabilities may have Down's Syndrome, traumatic brain injury, fetal alcohol syndrome, alcohol-related birth defects or other undefined disabilities.

A Learning Disability *affects the way people with average or above average intelligence take in, process or express information*. Learning disabilities are permanent, range from mild to severe, and encompass a group of disorders. Common learning disabilities include problems with memory, attention, reading, writing, arithmetic, reasoning, social skills, emotional maturity and coordination.

Please do not complete the Parent/Caregiver Questionnaire if the person you care for has a psychiatric disability/illness and no other type of disability.

The **Parent/Caregiver Questionnaire** collects information on YOUR needs as an individual who is responsible for the care of a person(s) with a disability(ies). If you SHARE these responsibilities with another person, please complete the **Parent/Caregiver Questionnaire** with this other person. If you need help to complete this Questionnaire, please ask for assistance from the Community Service Provider who gave you the questionnaire or from another adult in the community.

At any time, if you are uncertain about providing information or answering the questions, you can talk to the Community Service Provider or contact Sandy Auchterlonie, Lois Little or Bob Stephen at Lutra Associates collect at (867) 920-2177 or by fax (867) 873-8368 or via e-mail at xlutra@ssimicro.com

If you prefer to receive this Questionnaire in an alternate format (eg. orally), you can contact the people at Lutra Associates.

It should take between 20 and 30 minutes to complete the **Parent/Caregiver Questionnaire**. One **Parent/Caregiver Questionnaire** should be completed for each person you care for with a disability(ies).

Please complete and return this Questionnaire within 4 weeks of receiving it.

The information that you provide is CONFIDENTIAL. No one will know what you said or be able to identify you as a result of the information that you provide. All the information will be summarized on a community and a regional basis.

When you have completed the **Parent/Caregiver Questionnaire**, please return it to the Community Service Provider who first gave the Questionnaire to you. Community Service Providers take an oath of confidentiality so you should not worry about these people seeing the information that you provide.

Part A: About the Person With a Disability(ies) Who You Care for Some or All of the Time

1a. The person who you care for with a disability(ies) is:

❒ Male ❒ Female

1b. This person was born in: 19___

2. What is <u>your relationship</u> to this person?

❒ mother or father ❒ daughter or son ❒ grandparent
❒ sister or brother ❒ grandson or granddaughter ❒ aunt, uncle or cousin
❒ nephew or niece ❒ foster/trustee/guardian relationship
❒ other (explain)_____

3. Please indicate the <u>type of disability</u> that this person who you care for has.

Please refer to the definitions on page 1. Check (✓) all that apply.

❒ Physical ❒ Sensory
❒ Cognitive ❒ Intellectual
❒ Learning ❒ Don't know
❒ Psychiatric (only if present with another disability)

4. Has this person's disability(ies) been diagnosed, assessed or named by a professional? *Please find the type of disability(ies) that this person has. Check (✓) 'yes' if the disability(ies) has been diagnosed, assessed or named by a professional or check (✓) 'no' if it has not.*

Type of Disability	Diagnosed/Assessed/Named Yes	No
Physical	❒	❒
Sensory	❒	❒
Cognitive	❒	❒
Intellectual	❒	❒
Learning	❒	❒
Psychiatric	❒	❒

5. What behaviour(s) or characteristic(s) show this person's disability(ies)?
Think about all of the behaviours, traits or characteristics that the person shows day to day which indicate to you that this person has a disability(ies). Check (✓) all that apply

Behaviours and/or Characteristics Showing Some Level of Disability
Delay Developing, Difficulty with and/or Loss of:
❒ ability to move around/mobility
❒ hand/eye or physical coordination
❒ ability to move quickly or easily/agility
❒ strength, holding or lifting things
❒ balance or posture
❒ speech/ability to speak
❒ seeing things/vision
❒ hearing sounds/words
❒ understanding words/verbal comprehension
❒ remembering/memory
❒ learning new things
❒ learning from mistakes or life experiences
❒ controlling emotions (eg. anger, fear)
❒ controlling physical strength
❒ controlling tendency for physical violence
❒ focusing or paying attention
❒ behaving in a socially acceptable way
❒ understanding relationships/friendships
❒ verbal communication skills
❒ understanding/comprehension
❒ writing
❒ spelling
❒ reasoning
❒ reading
❒ calculation/understanding of numbers
❒ other (explain) _____
❒ other (explain) _____
❒ other (explain) _____
❒ other (explain) _____
❒ other (explain) _____

6. In your opinion, is this person's disability: *Please check (✓) <u>one</u> only.*

❒ Slight ❒ Moderate ❒ Somewhat Severe ❒ Very Severe

Part B: Your Needs as a Caregiver of a Person With a Disability(ies)

7. Does this person with a disability(ies) live with you: *Please check (✓) one only.*

❒ all of the time?
❒ part-time (eg. week-ends, one or two weeks per month)?
❒ not at all?
❒ once in a while (eg. special occasions)?
❒ other (explain)_____

8. How much time do you spend each week caring for this person? *Check (✓) one only.*

❒ less than 10 hours
❒ 10 to 30 hours
❒ more than 30 hours
❒ constant (24 hour supervision)
❒ other (explain)_____

9a. What services/programs do you use now to help you to care for this person with a disability(ies)? Check (✓) all that apply. The programs/services listed below are ones that you might need as a caregiver. They are not the services that the individual you care for may need - these are listed in the **Personal Questionnaire**.

9b. What services/programs do you need but do not use now, to help you to care for this person with a disability(ies)? Check (✓) all that apply.

	Q9a. Use NOW	Q9b. Need NOW
- respite for myself	❒	❒
- home care services	❒	❒
- support in the home when the person with a disability visits	❒	❒
- transportation to get to appointments	❒	❒
- transportation to visit the person with a disability	❒	❒
- special equipment/tools/services/support	❒	❒
- money to cover the costs of special equipment/tools	❒	❒
- money to cover the care of the person with a disability	❒	❒
- help to communicate with teachers/health centre/other professionals	❒	❒
- help to advocate to get services for the person with a disability	❒	❒
- information about this type of disability	❒	❒
- information about services and benefits	❒	❒
- information about caring for a person with this disability(ies)	❒	❒
- information about how to look after myself/other family members	❒	❒
- understanding and support from people in the community	❒	❒
- understanding and support from service agencies in the community	❒	❒
- other (explain).....	❒	❒

.....

.....

10. Do you pay for any of the services that you use now? ❒ Yes ❒ No

11. What are the <u>good</u> things <u>about caring</u> for this person with a disability? Think about the things that are rewarding for you. Check (✓) all that apply.

❒ finding ways to overcome problems
❒ learning more about disabilities
❒ the way our family works together to help
❒ receiving love from this person
❒ teaching and showing this person how to do things
❒ helping this person feel good about her/himself
❒ getting help and support from my community
❒ seeing this person becoming independent
❒ helping to change attitudes about disabilities
❒ giving love to this person
❒ other (explain).....
.....
❒ other (explain).....
.....

12a. What are the most <u>challenging</u> things <u>about living with or caring</u> for this person with a disability for you personally and in terms of providing care/support? Think about the things that create problems for you. Check (✓) all that apply.

Personal Challenges

❒ keeping myself healthy
❒ being responsible for this person all the time
❒ finding time to spend with other family members
❒ balancing work, play, family and life in general
❒ finding enough money for myself and my family
❒ not having time to be involved in the community
❒ being with this person all the time
❒ finding time for myself
❒ getting emotional support for myself
❒ taking time away from work
❒ trying to be patient with the person
❒ trying not to blame the person
❒ other (explain .....
.....

Providing Care/Support

❒ looking after the person's personal care needs
❒ dealing with the person's negative behaviours
❒ moving the person (eg. from the bed to a chair)
❒ getting the proper aids or equipment
❒ getting professional help for the person
❒ getting help to deal with the person's mental health
❒ finding supports/services
❒ getting cooperation from the person
❒ communicating with the person
❒ dealing with new service providers
❒ other (explain).....

12b. What other challenges do you experience living with or caring for this person with a disability? Check (✓) all that apply.

Other Challenges

- ❒ getting support from others in community
- ❒ dealing with community attitudes
- ❒ dealing with the attitudes of professionals and/or other service providers
- ❒ worrying that others may harm the person
- ❒ worrying that the person may harm him/herself
- ❒ worrying that the person may harm others
- ❒ the person's abuse of substances
- ❒ talking to the person about his/her disabilities
- ❒ finding education/training for the person
- ❒ worrying about the person becoming pregnant or parenting
- ❒ finding enough money to look after the person
- ❒ finding a place for the person to live
- ❒ other (explain).....
- ❒ other (explain).....

13. If for some reason the person with a disability could not live where he/she is living now, where could this person live?

- ❒ another member of our family would care for him/her
- ❒ another person in the community would care for him/her
- ❒ he/she would have to move outside the community
- ❒ he/she could move to a community facility (eg. seniors facility, group home)
- ❒ haven't thought about this
- ❒ don't know
- ❒ other (explain).....

14. What did we forget to ask you about your needs as a caregiver of a person with a disability? Please add your comments here.

_____

_____

_____

_____

Please complete and return this Questionnaire to the Community Service Provider who gave it to you, within 4 weeks of receiving it. THANK YOU FOR YOUR TIME AND INPUT INTO THIS NEEDS ASSESSMENT.

APPENDIX D: COMMUNITY TEAM MEMBERS

Needs Assessment of Persons with Disabilities - Community Team Members

(including local researchers)

BEAUFORT

Paulatuk
Sadie Ruben, Community Wellness
Adelle Dyall, NIC, Paulatuk Health Centre
Bill Kudluk, CHR, Paulatuk Health Centre
Irene Ruben, Coordinator, Paulatuk Preschool
Richard Ruben, Community Wellness Worker, Inuvialuit Regional Corp.
Annie Thrasher, Paulatuk Housing Association
Phoebe Ruben, Income Support
Trudy McClements, Community Social Services
Senior Administrative Officer, Hamlet of Paulatuk
Marlene Wolki, Researcher

Sachs Harbour
Shirley Esau, Community Health Representative
Peggy Lucas, NIC, Sachs Harbour Health Centre
Kelly Carpenter, Child Development Centre
Lorna Dillon, Community Wellness, Inuvialuit Community Corp.
Yvonne Elias, Housing Association
Joanne Carpenter, Income Support

Holman
Tony Kulbisky, Community Wellness
Linda Huchkowsky, NIC, Holman Health Centre
Alice Kimiksana, CHR, Holman Health Centre
Ron Wilson, Community Learning Centre
Rita Banksland, Coordinator, Child Development Centre
Sarah Kuptana, Community Wellness Worker, IRC
Colin Okheena, TRO, Holman Housing Association
Joyce Banksland, Income Support
Barbara Memogana, Researcher

Tuktoyaktuk
Lucy Dillon, Community Mental Health Worker
Paula Gregory, Community Social Services Worker
Shawn Hoey, Community Social Services Worker
Jenny Jacobson, Child Development Centre

Lynn Jullian, Income Support
Michelle Skanes, Community Learning Centre
Fred Kuptana, Tuk A&D Centre
Ada Cockney, Community Wellness, ICC
Reenie Palmer, NIC, Health Centre
Anita Pokiak, CHR, Health Centre
Lucille Pokiak, Tuk Housing Assoc.
Warren Schofer, Community Corrections
Recreation Coordinator, Hamlet of Tuk
Vera Ovaynak, Researcher
Shelia Taylor, Researcher

MACKENZIE DELTA

Inuvik

Wendy Mepham, Homecare Coordinator, Inuvik Regional H&SS Board
Donna Kisoun, NWT Training Centre
Arlene Jorgenson and Cathy Shortt, Inuvik Family Counselling
Dennis Inglangasuk, Turning Point
Tracy McPherson, Inuvik Probation and Parole Services
Gloria Allen, Ingamo Hall Friendship Centre
Diana Tingmiak, TRO, Inuvik Housing Authority
Cathleen Smith, Occupational Therapy, Inuvik Regional H&SS Board
Amy Gordon, Physiotherapy, Inuvik Regional H&SS Board
Barb Lennie, Inuvik Public Health and Homecare
John Nash, Inuvik Justice Committee
Tracy Woodman, Student Services, Aurora College
Sharon Spangts and Sandra Suliman, Inuvik Social Services
Cathy Ross and Merrick Naporkorski, Researchers

Fort McPherson

Kim McLeod, Community Social Services Worker
Tetlit Zheh Child Centre
Abe Stewart, Income Support
Lloyd Hyatt, Community Learning Centre
Mary Ross, Tl'oondih Healing Camp
Beatrice Blake, Peel River Alcohol and Drug Centre
Jackie Ryan, A/NIC, Health Centre
Winnie Greenland, CHR, Health Centre
Shirley Wilson, TRO, Ft. McPherson Housing Assoc.
Wilbert Firth, Manager, Tetlit Gwich'in Council
Edna Alexie and Karen Colin, Researchers

Tsiigehtchic
Carol Norwegian, CHR, Health Centre
Courtnae Clark, NIC, Health Centre
Linda Andre, Income Support
Elaine Blake, Recreation Coordinator
Tsiigehtchic Day Care
Olive Blake/Anna May McLeod, Alcohol and Drug
Corrine Dillon, Researcher

Aklavik
Elizabeth Kunnizi, Alcohol and Drug Program,Aklavik United Friendship Centre
Gladys Edwards, Community Social Services Workers
Eugene Pascal, Aklavik Aboriginal Committee
Terry Peterson, Joe Greenland Centre
Flora Elanik, Aklavik Housing Association
Diane Gordon, CHR, Aklavik Health Centre
Nurse in Charge, Aklavik Health Centre
Faye Gordon, Community Wellness, Aklavik Community Corp.
Eva Gordon, Coordinator, Aklavik Preschool
Mary Storr, Community Counselling Service
Cheryl Johnson, Community Learning Centre
Sandra Arey, Income Support Worker
Shauna Gordon, Researcher

SAHTU

Colville Lake
Sharon Tutcho, CHR
Marie Kotchon, A&D Worker, Behdzi Ahda First Nation
Joseph Kochon, Band Manager, Behdzi Ahda First Nation

Fort Good Hope
Karen Shublyn-Moldnar,Community Social Services Worker
Chief Delphine Pierrot, K'asho Got'ine Community Council
Florence Barnaby, Family Violence Program
Sue Morency, Fort Good Hope Daycare
Justice Coordinator, K'asho Got'ine Community Council
Chris Jackson, Seniors' Residence
Henry Tobac, CHR, Health Centre
Marilyn Lidstone, Health Centre
Wolfgang Bauman, Community learning Centre
Phoebe McNeeley, Income Support Officer

Robert Kelly, K'asho Got'ine Alcohol and Drug Program
Angela Grandjambe, Radilih Koe' Housing Association
Patricia McKeon, Family Counsellor
Darrell Cook, Employment Officer

Tulita
Bertha Lennie, Tulita Wellness Agency
Elaine Doctor, Community Social Services
Rita Doctor, Employment Officer
Andrea Dougherty, NIC, Tulita Health Centre
Joanne Fraser, CHR, Tulita Health Centre
Theresa Etchinelli, A&D Worker
Stephanie O'Brien, Community Learning Centre
Tulita Child Development Centre
Lillian Doctor, Researcher

Norman Wells
Dennis Farley, Mental Health Counsellor, Town of Norman Wells
Linda Lasch, Health Centre
Tony Harrison, Health Centre

Deline
Rosemary Elemie, A&D
Carolyn Yukon, Community Social Programs
Ann Bayha, Housing
Lori Morgan, Nurse in Charge
Betty Tetso, CHR, Deline Health Centre
Brenda Baton, Employment Officer
Jane Modeste, Income Support
Chris Courage, Community Learning Centre
Deline Preschool
Camilla Tutcho, Researcher

DEH CHO

Fort Simpson
Pearl Norwegian, Metis Local
Charles Jacobson, Career Centre
Hilda Gerlock, Housing Authority
Nicole Barrington, Melaw Child Care
Pat Swartzer, Fresh Start Addictions Program
Valerie Stark, Open Door Society

Mel Sabourin, Friendship Centre
Leah Keats, Homecare Coordinator
Barb Tsetso, Adult Educator
Debbie Antoine, Social Services
Sheila Sears, Health Clinic
Karen McCorresten, Stanley Isaiah Senior's Facility
Louisa Moreau, Researcher
Joyce Moses, Researcher
Louisa Moreau, Researcher

Fort Providence
Allan Bouvier, Housing Association
Margaret Field, Community Learning Centre
Joyce Villeneuve, Aboriginal Head Start
Allyn Rohatyn, A&D Program
Faye Stark, NIC, Health Centre
Wilma Field, Zhati Koe Friendship Centre
Albertine Nadli, Seniors' Facility
Leonie Sabourin, Researcher

Kakisa
Ruby Landry, Band Manager

Wrigley
Vicki Maloney, Lay Dispenser
Jeanine Gaulin, NIC, Fort Simpson
Bill Bertrand-Williams, Justice Coordinator
Eric Menicoche, Community Wellness Coordinator
Stella Pellisey, Pehdzeh First Nation Council
Etonia Hardisty, Researcher
Peter Moses, interpreter

Jean Marie River
Lucy Simon, Lay Dispenser

Trout Lake
Ruby Jumbo, Band Manager
Brenda Jumbo, Researcher
Phoebe Punch, Researcher

Nahanni Butte
Joan Ekotla, Lay Dispenser
Pauline Campbell, Band Manager

Fort Liard
Lynn Morin, NIC, Health Centre
Judy Kotchea, Acho Dene First Nation
Bernice Hardisty, Community Health Rep.
Mike Drake, Community Social Worker
Sandy Chalifoux, A&D Worker
Albertine Bertrand, Home Care
Emma Bertrand, Home Care
Susan Kotchea, Brighter Futures
Marie Kotchea, Researcher

SOUTH SLAVE

Fort Resolution
John Young, CEO, Fort Resolution Health and Social Services
Elizabeth MacKay, Housing
Terry Larocque, Social Services
Ruthie Mandeville, Deninu First Nations
Trina Norn, Income Support
Peter McCall, Health Centre
Gail Beaulieu, Health Centre
Dolly Lafferty, Alcohol and Drug Program
Eva Villeneuve, Mgr. Seniors' Facility
Elizabeth Giroux, CHR, Health Centre
Noleen Villebrun, Researcher

Hay River
Gary MacDonald, Occupational Therapy, Hay River Community Health Board
Raafat Ramzy, Physiotherapy, Hay River Community Health Board
Karen Ennis, Woodland Manor
Marilyn Lea, Hay River Housing Authority
Betty Lyons/Angela Libby, Soaring Eagle Friendship Centre
Liz Pope, Aurora College
Sharon Sunrise, Judith Fabien Senior Centre
Rita Plunkett, Home Support Worker, Hay River Reserve
Rhonda Latimer, Hay River Playschool
Quinn Groenheyde, Dene K'onia Young Offenders Facility
Deb Beck, Dene K'onia Young Offenders Facility

Sharon Cardiff, Extended Care Unit, Hay River Community Health Board
Karen Cooper/Pam Villeneuve/Martha Lenoir, Education, Culture and Employment
Mike Morrill, Hay River Community Health Board
Joanne Connors/Wanda Budgell, Aboriginal Headstart Program
Deb Stephen, Hay River Community Health Board
Shirley LaMalice, Hay River Dene Band First Nations
Mary King, Community Advocate
Jennifer McSwain, NWT Council for Disabled Persons

Enterprise
Bonnie Kimble

Fort Smith
Pamela Bradley, Homecare, Fort Smith Health and Social Service Board
Moira Jones, Public Health, Fort Smith Health and Social Service Board
Paulette Heron, Director Patient Services, Fort Smith Health Centre
Joan Bevington, Physiotherapy, Fort Smith Health and Social Service Board
Jessica Hval, Fort Smith Community Day Care
Ruth White, Fort Smith Housing Authority
Cheryl Comin, Mark Bradley, Northern Lights Special Care Home
Beatrice Campbell, Fort Smith Seniors Society
Sister Agnes Sutherland, Fort Smith Society for Disabled
Mary Lou Garlik, Cathy Walterhouse, Territorial Women's Correctional Centre
Cathryn Craik/Marisa Monchuk/Ethel Chalifoux, Education Culture and Employment
Brenda Gauthier, Director of Student Services, Aurora College
Sylvie Tordiff, Researcher

Lutsel K'e
Rachel Abel, A/CEO, Lutsel K'e Health and Social Services Board,
Anne Shackleton, NIC, Health Centre
Alizette Tatsiechele-Lockhart, CHR, Health Centre
J.C. Catholique, Community Wellness Coordinator
Emily Saunders, Social Services
Mary Rose Casaway, Housing

DOGRIB REGION

BethAnn Williams, Manager, Social Services, Dogrib Community Services Board
Anna Beales, Director of H&SS, Dogrib Community Services Board
Ruth Budgell, Home Care Coordinator, Dogrib Community Services Board
Phyllis Joy, Clinical Support Coordinator, Dogrib Community Services Board

Therese Koyina, Income Support Worker, Dogrib Community Services Board
Marcia Dean, Early Intervention Coordinator, Dogrib Community Services Board
Liz Richards, Home Care Course Instructor

Rae-Edzo
Bob Richardson, Executive Director, Rae-Edzo Friendship Centre
Rita Dryneck, Coordinator, Rae-Edzo Disabilities Committee
Tenant Relations Officer, Rae-Edzo Housing Authority
Alestine Mantla, Interpreter/Researcher
Rachel Ann Liske, Interpreter/Researcher
Linda McConnell, Social Development Coordinator, Dogrib Rae Band

Wha Ti
Mavis Moosenose, Wha Ti First Nation
Shirley Barnes, Health Centre
Alice Romie, Home Care Student
Larry Nitsiza, Researcher

Rae Lakes
Doreen Ann Apple, Rae Lakes Dene Band
Ron Ermann, Health Centre

Dettah and Ndilo
Gerry Cheezie, N'dilo Housing
Mary Jane Tsetta, Researcher

Yellowknife
Aggie Brockman, Ex. Dir., NWT Council for Disabled Persons
Kate Tymstra, Director Community Supports, YWCA
Jenifer Rigby, Alison MacAteer House
Miriam Wideman, Ex. Dir., Yellowknife Association for Community Living
Sue Edmonds, Yellowknife Association for Community Living
Christina Vernon, CNIB
Rae Celotti, HRDC, Disabled Peoples Strategy
Glora Kraft, Independent Clubhouse
Jan White, Learning Centre & Learning Disabilities Association
Sharon Ladd, Vocational Trade Centre
Darryl Bower, Avens/YACCS
Martha McLellan, Yellowknife Seniors Society
Barb Hood, NWT Seniors Society

Jan Stirling, Yellowknife Seniors society
Judith Todd, YCC
Anne Kennedy, Yellowknife Foster Parent Association
Al and Karen Hoeft, Salvation Army
Jennifer Legge, Colleen Chartrand Home
John Seagrave, Yellowknife Women's Centre
Tom Eagle, Helena Usherwood, Greg Krivda, Tree of Peace
Jeff Miniely, WCB
Kate Tompkins, Workers Advocate (WCB)
Liz Baille, Four Plus Program
Vita Morin, Income Support
Lorraine Sampson, Down the Block
Al Bowerman, Territorial Treatment Centre
Faye MacDonald, John Howard Society
Cate Sills, NWT Literacy Council
Elke Heinemann, Aurora College/YACL Literacy Outreach
Reanna Erasmus, Aboriginal Headstart
Mary Ellen Johnston, YACL FAS/FAE
Marjorie Matheson-Maund, Toy Library and Play Centre
Naomi Griffore, AIDS Yellowknife
Donna Allen and staff, Rehab Services, Stanton Reg. Hospital (OT, PT, S/L, Audiology)
Larry Pontus, Public Trustee
Ron McLellan, Office of the Public Guardian
Joanne Erasmus/Jan Lodge, Aurora College, Yellowknife Campus
Heather Leslie, Manager, Home Care Services
Karen Leidl/Kate Hamilton, Nurse Manager, Yellowknife Health & Social Services
Jim Bentley, A/Supervisor Child Protection, Yellowknife Health & Social Services
Liz Jackson, Foster Care Coordinator, Yellowknife Health & Social Services
Lynn Cooper, Special Needs/Community Development, Yellowknife H&SS
Barb MacDonald, Adult Probation Officer, Yellowknife Health and Social Services
Dean Gambin, Youth Worker, Yellowknife Health and Social Services
Sharon Cook, Extended Care Unit, Stanton Regional Hospital
Nancy Galloway, Yellowknife Housing Authority
Bobbi Bulmer, North Slave Housing Corporation
NWT Montessori Society
Val Braden, NWT Special Olympics
Dawn Anderson, Legal Aid Services
Ernie Glowich, Yellowknife Homeless Shelter
Bev Speight, Canadian Hard of Hearing Assoc., Yellowknife Chapter
Lynn Elkin, Autism NWT
Jennifer Turner-Beck, Native Women's Association

APPENDIX E: BIBLIOGRAPHY

BIBLIOGRAPHY

Adele Furrie Consulting Inc. June 1998. **Disability in Nunavut A Demographic Profile**. Nunavut Implementation Commission

Bureau of Statistics.1999. **NWT Labour Force Survey**. Government of the NWT

Canadian Disability Rights Council Conference. November 1989. "**Moving Forward on the Path to Equality**". Ottawa

Canadian Paraplegic Association. 1997. **Workforce Participation Survey of Canadians with Spinal Cord Injuries - Final Report**.

Coyne, Kathy. February 1994. **Mental Health Services in Fort Smith and Hay River A Needs Assessment - An Overview and Analysis of Current Capacity and Demand for Services**. South Slave Research Centre, Fort Smith

Dawson Consultant Services Ltd. November 1995. **Report on Northwest Territories Residents with Special Needs in Southern Placements**. GNWT Health and Social Services

Department of Health. September 1992. **Health and Health Resources Fort Smith - Community Profile**. Draft. Government of the NWT

Education, Culture and Employment. Spring 1993. **Student Support Services Information System Classroom and School-Community Profiles Analysis of Data Collection**. Government of the NWT

Environics Research Group Ltd. April 1989. **The Needs and Attitudes of Disabled Ontarians**. for the Office for Disabled Persons Ontario

Fawcett, Gail. 1996. **Living with Disability in Canada: An Economic Portrait**. Office for Disability Issues Human Resources Development Canada, Ottawa

Federal/Provincial/Territorial Ministers Responsible for Social Services. 1998. **In Unison: A Canadian Approach to Disability Issues - A Vision Paper**.

Report of the Special Parliamentary Committee on the Disabled and the Handicapped. 1980. **Obstacles.** Government of Canada, Ottawa

Federal Task Force on Disability Issues.1996. **Equal Citizenship for Canadians with Disabilities - the will to act**. Human Resources Development Canada, Ottawa

First Nations and Metis Rehabilitation Program and the Canadian Paraplegic Association (Alberta). no date. **Aboriginal Rehabilitation Counsellors' Training Manual.**

Health and Social Services. 1997. **Assessment of Level of Care Needs**. unpublished, Fort Smith

Health and Social Services. 1999. **The NWT Health Status Report**. Government of the NWT

Housing, Family and Social Statistics Division. April 1998. **User Guide Disability Data, the 1996 Census**. Statistics Canada

Inuvik Regional Health Board. February 1996. **Inuvik Region Update Aged, Disabled and Chronically Ill**. Department of Health and Social Services, Government of the NWT

Kinnon, Dianne. October 1994. **Health is the Whole Person- A Background Paper on Health and the Metis People**. Royal Commission on Aboriginal People, Ottawa

Lewis, Brian W. 1987. **Survey on Need for Information System About Mentally Handicapped in the NWT**. Yellowknife

Lutra Associates Ltd. June 1995. **Coming Home - Community Research into Intellectual Disabilities in Rae-Edzo**. Yellowknife Association for Community Living

_____October 1996. **Deh Cho Comprehensive Functional Review**. Department of Health and Social Services, Government of the NWT

_____October 1996. **Helping Families Helping Children Research into Fetal Alcohol Syndrome and Fetal Alcohol Effects**. Yellowknife Association for Community Living

_____ June 1997. **A Review of NWT Seniors Programs and Services.** NWT Seniors Advisory Council

Masuda, Shirley. March 1998. **The Impact of Block Funding on Women with Disabilities**. DisAbled Women's Network Canada

Minister's Forum on Health and Social Services. January 2000. **Our Communities Our Decisions - Let's get on with it! Final Report**. Health and Social Services, Government of the NWT

Nunavut Consulting. March 1995. **Psychiatric Housing and Services in the NWT - An Assessment of Needs.** Community Development Division, Department of Health and Social Services, Government of the NWT

Persons with Disabilities Project. October 1998. **"Potential.. Opportunity.. Progress.."** Human Resources Development Canada, Yellowknife

Peart, M. and King, A.J.C. January 1996. **Health Behaviours, Attitudes and Knowledge of Young People in the Northwest Territories**. Education, Culture and Employment, Government of the NWT

Ridington, J. March 1989. **Beating the "Odds": Violence and Women with Disabilities**. DisAbled Women's Network Canada.

Ross, David P. and Shillington, E. Richard. 1990. **An Economic Profile of Persons with Disabilities in Canada**. Department of the Secretary of State of Canada. Ottawa

SKR (Stan K. Remple) Management Consulting. 1995. **A Proposal for Community Supports to Enhance Independent Living for Persons with Intellectual Disabilities in the Northwest Territories**. for the Yellowknife Association for Community Living

Sappujjijit Friendship Centre. Fall 1994. **Enhancing the Life of Persons with Disabilities**. Rankin Inlet.

Sheppard, R. **"Why Kids Can't Read"** in Maclean's September 7,1998 p.41-44
_____ **"Growing up hyperactive"**in Maclean's September 7,1998 p.45-46
_____ **"Battling the system"** in Maclean's June 22,1998 p.46-47

Sister Agnes Sutherland. September 1988. **Needs Assessment for Seniors and Disabled Persons - Fort Smith, Northwest Territories**. Department of Social Services, Fort Smith

Sobsey, D., Gray, S., Wells, D., Pyper, D., Reimer-Heck, B. 1991. **Disability, Sexuality and Abuse - An Annotated Bibliography**. University of Alberta, Edmonton

Social Trends Analysis Directorate. November 1986. **Profile of Disabled Person in Canada**. Department of the Secretary of State of Canada, Ottawa

Statistics Canada. November 1994. **Selected Characteristics of Persons with Disabilities Residing in Households 1991 Health and Activity Limitation Survey**. Ottawa

Status of Women Council of the NWT. May 1996. **Keeping Women and Communities Strong - Women, Substance Abuse and FAS/FAE: An NWT Needs Assessment**. Yellowknife

Stephen, B. November 1997. **Fort Smith Functional Program Review**. Lutra Associates Ltd. Yellowknife, for the Fort Smith Health and Social Services Board

Treeline Planning Services Ltd. April 1995. **Seniors Housing and Social Needs Study - A Planning Tool to the Year 2005 The Beginning**. the NWT Seniors' Advisory Committee, Yellowknife

Van Bibber, Marilyn. March 1993. **FAS Amongst Aboriginal Communities in Canada: A Review of Existing Epidemiological Research and Current Preventative and Intervention Approaches**. Royal Commission on Aboriginal Peoples, Ottawa

APPENDIX F: GENERALIZING THE RESULTS OF THE NEEDS ASSESSMENT TO THE TOTAL NWT POPULATION WITH DISABILITY

Generalizing the Results of the Needs Assessment to the Total Population with Disability

The 1991 Health and Activity Limitation Survey (HALS) was used to derive an estimate of the total population with disability. The HALS is a post-censal survey that provides coverage of the entire population of the NWT and Nunavut. Wherever possible the definitions used in the Needs Assessment reflected those used in the HALS. As shown in Table 1, it is expected that 13.1% of the population living in households in the NWT in 1999 have a disability. As expected most persons that reported disabilities have mild disabilities (67%) while almost a quarter (23%) have moderate and one in ten (10%) have severe disability.

Table 1: Estimated 1999 NWT Population with Disabilities by Age and Severity based on 1991 HAL Post Censal Survey Rates

		Total Population	Persons with Disabilities Living in Households			
			Mild	Moderate	Severe	Total
Number		41,606	3,674	1,259	521	5,453
	0 - 14	11,337	763	66	27	856
	15 - 64	28,579	2,530	942	228	3,700
	65 - over	1,690	381	250	266	897
% of Disabilities			67.4%	23.1%	9.6%	100.0%
	0 - 14		89.1%	7.7%	3.2%	100.0%
	15 - 64		68.4%	25.5%	6.2%	100.0%
	65 - over		42.4%	27.9%	29.7%	100.0%
% of Population			8.8%	3.0%	1.3%	13.1%
	0 - 14		6.7%	0.6%	0.2%	7.6%
	15 - 64		8.9%	3.3%	0.8%	12.9%
	65 - over		22.5%	14.8%	15.7%	53.1%

Notes: Table 1 provides an estimate of the total number of persons with disability by severity living in households based on rates derived from the HALS and the NWT population[1] in 1999. Rates derived from the HALS-based degree of severity for each age group were applied to the NWT population in 1999 by age. This methodology assumes that the rates have not changed since 1991 and that the degree of disability by severity and age for persons living in Nunavut and the NWT are similar.

Two questions were posed to determine whether the Needs Assessment results could be applied to estimates of the total population of persons with disability in the NWT:

---

[1]NWT Bureau of Statistics, Population by Age for 1999

1. What portion of the total population with disability did the Needs Assessment cover?
2. Are Needs Assessment respondents representative of the total population of persons with disability so that Assessment results can be generalized to the total population?

Table 2 presents the number of persons with disability living in households and participating in the Needs Assessment by age and degree of disability.

Table 2: Needs Assessment Population Living in Households with Disabilities by Age and Severity

		Total	Persons with Disabilities Living in Households			
		Population	Mild	Moderate	Severe	Total
Number		41,606	85	209	379	673
	0 - 14	11,337	14	28	56	98
	15 - 64	28,579	44	123	211	378
	65 - over	1,690	27	58	112	197
% of Disabilities			12.6%	31.0%	56.3%	100.0%
	0 - 14		14.3%	28.6%	57.1%	100.0%
	15 - 64		11.6%	32.5%	55.8%	100.0%
	65 - over		13.7%	29.4%	56.9%	100.0%
% of Total Population			0.2%	0.5%	0.9%	1.6%
	0 - 14		0.1%	0.2%	0.5%	0.9%
	15 - 64		0.2%	0.4%	0.7%	1.3%
	65 - over		1.6%	3.4%	6.6%	11.7%

In total the Needs Assessment involved 85 of the expected 3,674 mild disabilities (2.3%), 209 of the expected 1,259 moderate disabilities (16.6%), and 379 out of the 521 expected severe disabilities (72.7%). (Table 3)

Table 3: Needs Assessment as Proportion of Estimated Population

Number		HALS	NA	NA % HAL
Mild		3,674	85	2.3%
	0 - 14	763	14	1.8%
	15 - 64	2,530	44	1.7%
	65 - over	381	27	7.1%
Moderate		1,259	209	16.6%
	0 - 14	66	28	42.4%
	15 - 64	942	123	13.1%
	65 - over	250	58	23.2%
Severe		521	379	72.7%
	0 - 14	27	56	207.4%
	15 - 64	228	211	92.5%
	65 - over	266	112	42.1%
Total		5,453	673	12.3%
	0 - 14	856	98	11.4%
	15 - 64	3,700	378	10.2%
	65 - over	897	197	21.9%
Moderate & Severe		1,780	588	33.0%
	0 - 14	93	84	90.3%
	15 - 64	1,170	334	28.5%
	65 - over	516	170	32.9%

This pattern was expected because the Needs Assessment was drawn from persons already seeking services due to disability, likely due to moderate to severe disability (e.g. persons with moderate to severe disability are more likely to be in the service loop than those with mild disability.) Table 3 also shows that if the moderate and severe disabilities are combined the Needs Assessment covered one-third (33%) of the expected population with disabilities.

The high proportion of the population covered by the Needs Assessment for the moderate and severe disability groups provide an opportunity to generalize results to the total population. The much lower coverage in the mild disability group makes generalization to the total population much less reliable.

The remaining question is whether there is any significant difference in the characteristics of the population with moderate and severe disability covered by

the Needs Assessment and those not covered by the Needs Assessment. If there are no basic differences, the Needs Assessment is representative of the entire expected population of persons with disability. It is the best professional judgment of the Lutra research team in consultation with Ellis Consulting Ltd. that there are no reasons to expect any differences in the populations covered by the Needs Assessment and the HALS. This means that the results of the Needs Assessment can be used to represent the entire estimated population of persons with disability.

Population Projections

The Needs Assessment represents one-third (33%) of persons with disability living in non-institutionalized settings. Based on data derived from HALS and the NWT population projection. Table 4 projects to the total number of persons with disability by severity living in households in the NWT from 1999 to 2019.[2] (Rates derived from HALS based on degree of severity for each age group were applied to the NWT population projections for each year by age. This methodology assumes that the rates have not changed since 1991 and that the degree of disability by severity and age for persons living in Nunavut and the NWT are similar.) As shown, it is expected that the population with disability will increase from 5,453 to 6,515 in 2009 to 8,883 in 2019.

[2]Source: NWT Bureau of Statistics, Population Projections by Age to 2019

Table 4: Projected Number of Persons Living in Households in the NWT with Disability by Age and Severity, 1999-2019

Number		1999	2004	2009	2014	2019
0 - 14		856	867	832	861	917
	Mild	763	772	742	767	817
	Moderate	66	67	64	66	71
	Severe	27	27	26	27	29
15 - 64		3,700	3,913	4,186	4,400	4,592
	Mild	2,530	2,676	2,862	3,008	3,140
	Moderate	942	997	1,066	1,121	1,170
	Severe	228	241	258	271	283
65 - over		897	1,130	1,497	1,980	2,373
	Mild	381	480	635	840	1,007
	Moderate	250	315	418	553	662
	Severe	266	335	444	587	704
Total		5,453	5,910	6,515	7,241	7,883
	Mild	3,674	3,928	4,239	4,616	4,964
	Moderate	1,259	1,379	1,548	1,740	1,903
	Severe	521	603	728	885	1,016

Rates		1999	2004	2009	2014	2019
Percent of Population		13.1%	13.5%	14.1%	14.7%	15.1%
	Mild	8.8%	9.0%	9.2%	9.4%	9.5%
	Moderate	3.0%	3.1%	3.4%	3.5%	3.7%
	Severe	1.3%	1.4%	1.6%	1.8%	1.9%
Percent Change			2.9%	4.6%	4.5%	2.7%
	Mild		1.5%	2.5%	2.4%	1.4%
	Moderate		4.0%	6.6%	5.6%	3.1%
	Severe		10.0%	14.5%	14.3%	8.2%

A partnership of:

Canada
Service Canada / Service Canada

Northwest Territories Health and Social Services

Human Resources Development Canada / Développement des ressources humaines Canada

Yellowknife Association for Community Living

Sombak'è dọne nàdè xà eghàlagìdè

YWCA

N.W.T. COUNCIL FOR DISABLED PERSONS

MaryAnne Duchesne